MINUTES OF THE MEETING OF THE EAST LOTHIAN INTEGRATION JOINT BOARD

THURSDAY 21 SEPTEMBER 2023
VIA DIGITAL MEETINGS SYSTEM

1

Voting Members Present:
Councillor S Akhtar (Chair)
Ms E Gordon
Ms F Ireland
Councillor C McFarlane
Councillor G McGuire* (*substitute*)
Mr P Murray

Non-voting Members Present:
Ms M Allan
Mr D Aston
Mr D Binnie
Ms L Byrne
Ms C Flanagan
Dr J Hardman
Dr C Mackintosh
Ms M McNeill
Mr T Miller
Ms F Wilson

Present from NHS Lothian/East Lothian Council:
Ms L Berry
Mr P Currie
Ms C Goodwin
Ms J Jarvis
Ms G Neil
Ms L Rowlinson

Clerk:
Ms F Currie

Apologies:
Councillor L Bruce*
Mr A Cogan
Councillor L Jardine**
Dr P Conaglen

Declarations of Interest:
None

*[**The substitute appointed by Councillor Jardine was unable to attend the meeting due to technical difficulties.]*

1. MINUTES OF THE MEETING OF THE EAST LOTHIAN IJB ON 22 JUNE 2023 (FOR APPROVAL)

The minutes of the IJB meeting on 22nd June were approved.

2. MATTERS ARISING FROM THE MINUTES OF THE MEETING ON 22 JUNE

The following matters arising were discussed:

Item 7 (2022/23 Draft Unaudited Annual Accounts) – The Chair noted discussion around ELC and Audit Scotland and expressed concern that the minutes did not accurately reflect what had taken place. Fiona Ireland confirmed that the question and the answer given at the meeting was that had been accurately reflected in the minutes.

The Chair wanted to highlight that the media coverage was factually inaccurate and she would like this reflected in the minutes.

Peter Murray suggested that the Chair's concerns could be recorded in the 'Matters Arising' from the minutes of this meeting and any further discussion could take place out with the meeting. The Clerk confirmed that the Chair's view could be recorded within 'Matters Arising' in the minutes of this meeting (21 September). Ms Ireland concurred with this suggestion.

Claire Flanagan stated that the main point from the last meeting had been whether the IJB should be concerned, or have the issue reflected in their accounts. She had clearly stated at that time that there was no need for concern. She had received letters of assurance from the partners, she was working through the audit process with Audit Scotland and there was no risk to IJB.

3. CHAIR'S REPORT

The Chair reported on a meeting of IJB Chairs/Vice Chairs which had included a helpful presentations, discussion and debate on the National Care Service (NCS), SSSC and funding for a national agency for social work. The meeting had also provided the opportunity to speak to the team dealing with governance and structures within the NCS and to feedback to them on the challenges from an East Lothian perspective.

Mr Murray indicated that a composite of presentations from the meeting had now been circulated to attendees and he said he would send to the Clerk for distribution to IJB members.

The Chair also informed members that further events were planned on the NCS, including in Edinburgh. This was an area which the IJB would need to keep in view, to ensure that the new body would offer the least level of bureaucracy and would strengthen and support the positive work already done by IJBs across the country.

The Chair also informed members of the following events:

A Dementia-friendly East Lothian event in Haddington which brought together groups from across county to reflect on the establishment of the new centre in Musselburgh and to provide the opportunity for them to contribute to the new dementia strategy for East Lothian.

The publication of the Census information which had highlighted that between 2011 and 2022 East Lothian saw a population increase of 12.6%; the second highest in Scotland.

A recent development session for IJB members on primary care and prescribing and the challenges facing both areas.

A very useful adult mental health wellbeing network event which had brought together groups from across East Lothian.

Meetings with Keep the Heid, a local mental health charity.

A Care and Repair Board meeting this morning to support people coming out of hospital.

The Chair invited members to contact her is they would like further information of any of the events/issues raised in her report.

4. QUARTER 1 FINANCIAL FORECAST FOR 2023/24

A report was submitted by the Chief Finance Officer laying out the results of the partner's (East Lothian Council and NHS Lothian) quarter one financial reviews and considering how these impact on the projected financial position of the IJB for 2023/24. It also reports on the quarter 1 monitoring of the IJB financial recovery plans and the current reserves position.

Before presenting her report Claire Flanagan informed members that the IJB's annual accounts for 2022/23 and the annual external audit report had been delayed. This was caused by resource issues within Audit Scotland's audit team and their desire to conclude testing within East Lothian Council before finalising the IJB's audit. John Boyd, audit director, had attended the recent Audit & Risk Committee meeting to inform members of the delay and the reasons for this.

Ms Flanagan then turned to her Quarter 1 financial report. She informed members that the IJB's forecast overspend for the year-end was currently £8.5M. The main drivers of which related to the prescribing and set aside budgets within health, and commissioned services within social care. She advised that some data had still to be fed into these forecasts and it was likely that these figures would be revised down, once this information was available. The figures would be further improved by the IJB receiving a share of additional Scottish Government funding to support sustainability and new medicines funding, and if East Lothian Council approved the passporting to the IJB of any additional Scottish Government funding to support the local authority pay settlement.

Ms Flanagan also drew attention to the financial recovery plans set out in the report and the general reserves position.

Ms Flanagan responded to questions from Mr Murray. She advised that the HSCP were looking at putting in place additional controls and escalation processes to address issues around care home beds and learning disability placements and bring these back within affordability levels. Regarding the set aside budget, she advised that while this was not managed by the HSCP, colleagues from NHS Lothian were routinely invited to present to the Board on the issues around the set aside budget.

Mr Murray acknowledged that that there continued to be significant pressure on care home beds and it would be interesting to see what impact these actions would have. On set aside budgets, he agreed that additional insight would be helpful and may help the IJB to understand what opportunities it might have to influence things going forward.

Ms Flanagan agreed to request that a presentation be given to IJB members.

In response to a question from David Aston, Ms Flanagan confirmed that the delay in finalising the accounts and annual audit was a result of resource issue within Audit Scotland and that no issues had been raised following a review of the first draft of the accounts.

SA – met of chairs/vice chairs; finance office from Glasgow; engagement with SG around challenges; any advice from SG re use of reserves or clawing back of reserves?

Replying to questions from the Chair, Ms Flanagan advised that a lot of work had been done by CFOs to feedback to the Scottish Government on the financial challenges facing IJBs. A joint report had been prepared at budget time which had been shared with CoSLA, Directors of Finance and Scottish Government, and there was a shared ambition to produce a further iteration of this report. In addition, IJBs continued to submit quarterly returns to the Scottish Government.

On the issue of recovery plans, Ms Flanagan stated that these plans had been assessed and consideration had been given to whether impact assessments were required. At present, recovery plans focused mainly on operational changes but going forward it was likely that these plans would include strategic and policy changes which would require integrated impact assessments.

The Chair thanks Ms Flanagan for her report. She noted the importance of monitoring financial processes and of highlighting the challenges facing IJBs. She referred to the recent visit to east Lothian by the Deputy First Minister which had provided an opportunity to highlight the challenges faced by significant population growth within the county.

Decision

The IJB agreed to:

i. Note the quarter one financial review undertaken by partners;
ii. Note the update on financial recovery plans; and
iii. Note the IJBs general reserve position.

5. INTERIM APPOINTMENT OF CHIEF FINANCE OFFICER

A report was submitted by the Chief Officer informing the IJB of the intention to temporarily appoint a Chief Finance Officer/Section 95 Officer (CFO) to cover the vacancy created by the departure of the current postholder, until such time as the substantive post is filled.

Paul Currie presented the report. He outlined the process for the temporary appointment of new CFO, while arrangements were put in place to appoint substantively to the vacancy created by Ms Flanagan's departure. The report also set out the regulations and requirements and highlighted that the CFO role was a joint appointment with Midlothian IJB. The recruitment process would be undertaken in conjunction with Midlothian IJB, as well as East Lothian Council and NHS Lothian.

The Chair thanked Ms Flanagan for her contributions as CFO over the past few years and wished her well in her new role.

The Chair then moved to the vote on the recommendations, which was taken by roll call and approved unanimously.

Decision

The IJB:

i. Agreed to the proposal to recruit, as an interim arrangement, cover for the Chief Finance Officer/Section 95 Officer vacancy, resulting from the departure of the previous postholder;

ii. Delegated authority to the Chief Officer and Chair of the IJB to approve the interim appointment on the IJB's behalf after the recruitment process; and

iii. Noted that an update on the outcome of this process will be provided at a future IJB meeting.

6. CHANGES TO THE IJB MEMBERSHIP

A report was submitted by the Chief Officer informing and seeking approval from the IJB regarding changes to its non-voting membership.

Fiona Wilson presented the report. She outlined the changes to the non-voting membership, as set out in the report.

The Chair thanked Lorraine Cowan for her contributions to the IJB and the HSCP and wished her well in her new role. She also welcomed John Hardman and David Hood to the IJB.

Dr Hardman apologised for missing the recent development session and said he looked forward to contributing to the work of the IJB going forward.

The Chair moved to the vote on the recommendations, which was taken by roll call and approved unanimously.

Decision

The IJB:

(i) agreed the appointment of Dr John Hardman as a non-voting member of the IJB for the maximum term of office;

(ii) agreed the appointment of Sarah Gossner as a non-voting member of the IJB, replacing Lorraine Cowan in the role of Chief Nurse, for the maximum term of office; and

(iii) noted the appointment of David Hood as a non-voting member of the IJB, replacing Iain Gorman in the role of Head of Operations within East Lothian HSCP.

7. EAST LOTHIAN IJB REVISED JOINT INTEGRATION SCHEME 2023

A report was submitted by the Chief Officer informing the IJB of the approval by Scottish Ministers of a revised Joint Integration Scheme, jointly developed by NHS Lothian and East Lothian Council.

Mr Currie presented the report. He reminded members of the need to review the Integration Scheme and outlined the background to the process which had been taken forward by NHS Lothian, in conjunction with the Council, during March 2023. He noted that although the IJB did not have a formal role in the review process, IJB members had been invited to offer views as part of a broader consultation exercise. The revised Scheme had now been approved and he commended it to members.

Mr Murray suggested that the IJB consider the aspirations set out in the Scheme, in particular around tackling health inequalities and investing the resources of the health and social care economy wherever it would have the greatest impact in meeting shared objectives; and addressing the significant challenges facing the HSCP.

The Chair echoed the remarks made by Mr Murray and noted some of the main changes to the Integration Scheme.

Decision

The IJB:

i. Noted the process for the development of the revised Integration Scheme and the external factors causing delays to its completion;

ii. Noted that although notification of the revised Scheme's approval was only formally received in July 2023, the revisions within have applied to the IJB from 15th May 2023;

iii. Noted that the next review of the Integration Scheme would be in 2028, unless otherwise directed by Scottish Ministers; and

iv. Noted that the revised Scheme was presented to the East Lothian Strategic Planning Group on 24 August 2023.

8. EAST LOTHIAN COMMUNITY HOSPITAL (ELCH) WARD 5 ORTHOPAEDIC REHABILITATION

A report was submitted by the Chief Officer informing IJB members of the development of NHS Lothian's use of Ward 5 of East Lothian Community Hospital (ELCH) for the provision of in-patient orthopaedic rehabilitation, as part of its Orthopaedic Recovery Plan. The Ward opened to the first 8 patients week beginning 4 September 2023.

Ms Wilson presented the report. She outlined the background to the development of the orthopaedic rehabilitation provision at ELCH and provided details of the anticipated type and number of procedures the service would be supporting. She noted that the development of this service would also provide the opportunity for the ELCH to become a centre of excellence.

Mr Murray offered his full support for the proposals and recognised the benefits for East Lothian residents.

Elizabeth Gordon echoed these sentiments and asked how many East Lothian residents were likely to use the service. Ms Wilson said it was a Lothian-wide service and allocation would be done on a list basis, involving those patients were ready first, rather than prioritising East Lothian residents. She added that there had already been some very good feedback from patients, and she hoped this could be shared with IJB members.

Replying to a question from Councillor McGuire, Ms Wilson explained that while ELCH was not equipped to carry out surgery it was very well designed to provide rehabilitation services for patients when they no longer needed acute care.

Jennifer Jarvis said she had provided members with links to feedback videos and further information on the service. This information had also been shared with patients and families prior to their use of service.

Dr Hardman said that clinicians were convinced that this was a positive step and a lot of work had been undertaken to ensure it was as safe as possible. He also commended the rehabilitation team for their proactive approach to delivering effective rehabilitation.

Replying to a question from the Chair, Ms Wilson acknowledged that workforce remained a challenge. A great deal of work had been done to produce a plan to recruit non-registered and trained staff to allow the expansion of the service up to the maximum of 24 beds.

The Chair added her support for the work being undertaken and thanked the team for their efforts in supporting this service and in helping patients to get home as soon as possible.

Decision

The IJB:

i. Noted the development by NHS Lothian for orthopaedic rehabilitation in-patient provision at ELCH; and

ii. Noted the positive impact of this development for East Lothian residents and for ELCH, and that funding would be through the Elective Recovery Programme, with no direct financial implications for the East Lothian IJB.

9. EAST LOTHIAN IN-REACH PROJECT AT THE ROYAL INFIRMARY OF EDINBURGH

A report was submitted by the Chief Officer updating the IJB on ongoing development and delivery of the In-reach Programme.

Laura Rowlinson gave a presentation providing a brief overview of the In-Reach programme being run by the rehabilitation service within RIE. She outlined the overall approach, staffing resource, funding and project activity during Phase 1 and Quarter 1 of Phase 2. She advised that data gathered during Phase 1 had helped to refine services in Phase 2 and further support discharge planning, including the design of an early intervention assessment for patients in A&E. She concluded that the project had a data-driven ethos and a flexible approach which had allowed them to adapt and refine services and data would continue to be gathered and analysed to further improve services.

Mr Murray asked about identifying the anticipated savings that might accrue and whether this project could be submitted to the Scottish Government as an example of good practice, should the evaluation deem it to be successful and sustainable.

Ms Wilson said that the work had already been flagged to Scottish Government, and NHS Lothian were also keen to develop the project with a view to gaining a broader impact across Lothian. The project had challenged current roles and responsibilities and the culture of where rehabilitation and assessment could take place. She added that it

was important to take things a step further and have conversations about shifting the balance of care, getting better and earlier intervention and scaling up good practice.

Dr Claire Mackintosh commended the project from a 'front door' perspective but said that work was needed by clinicians to improve the consistency of approach for patients from different areas. She also particularly liked the assertive case finding approach adopted by the team.

Ms Wilson agreed with this comment and the need to influence shifts in roles and responsibilities and better support discharge planning, and good outcomes for patients.

Dr Hardman commended the project but said it was equally important to consider what can be learned from engagement with staff to date and how this can be used to improve service delivery in future.

Ms Rowlinson advised that there had been lots of learning gained and the general response within RIE had been very positive. She said that in East Lothian, staff were very innovative and liked change, however, not everyone had that approach and a significant amount of communication and relationship building had been required. Getting people invested was an ongoing process but improving buy-in would enhance profile of HSCP and improve the success of project going forward.

Maureen Allan said that it was also important to engage with the community and build capacity within community services to help support patients' rehabilitation journeys.

Lesley Berry acknowledged that it would not be possible to deliver this project without the third sector and other partners, and the support of the community in East Lothian. It had been difficult at the 'front door' and on the wards at times. However, her staff had agreed at beginning that they would be totally professional and would keep going despite the challenges. She complimented the team members on their ability to maintain their professionalism and she noted that things had started to improve.

In reply to a question from the Chair, Ms Rowlinson agreed that the case studies were good to read and there were many to choose from. She confirmed that new case studies would be added to the forthcoming six-monthly report.

Mr Murray referred to the comments made by Ms Berry and Dr Mackintosh relating to the challenges associated with the challenges resulting from staff working together on this project and how these can be reconciled going forward; and the need to improve consistency of this work across all 4 Lothian IJB areas. He hoped that the clear potential benefits for patients and staff should be sufficient to allow teams to navigate their way through individual challenges. He also hoped that the project could be promoted as good practice beyond the borders of Eats Lothian.

Ms Wilson said that as Unscheduled Care Programme Chair she was already trying to do this. There were significant cultural issues around bringing people along with the project and finding a pace people were comfortable with. However, the management team within NHS Lothian were very supportive and further development of this service was the shared ambition of all partnerships working across Lothian.

In response to questions from the Chair, Ms Wilson advised that unscheduled care monies had funded the project to date. Evaluation of the project had provided the data to support a wider conversation around set aside and this would be the next stage in the process. She also acknowledged that communication and engagement with communities was key to ensure people were aware of the service.

Ms Jarvis offered to create a press release, based on the information in Ms Rowlinson's report, and circulate widely to promote the positive outcomes from this work.

Decision

The IJB agreed to note the positive evaluation of Phase 1 of the In-reach Project and the agreement to continue delivery until March 2024.

Signed .....

Councillor Shamin Akhtar
Chair of the East Lothian Integration Joint Board

REPORT TO: East Lothian Integration Joint Board

MEETING DATE: 26 October 2023

BY: Interim Chief Finance Officer

SUBJECT: Financial Update – 2023/24

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1 PURPOSE

1.1 This report discusses the following –

i) The IJB's financial position as reported by its partners at Month 5 (August 2023).

ii) An update on the financial planning process and an outline for 2024/25 and beyond.

iii) An update on the preparation of the 22/23 annual accounts

iv) The proposed transfer of funds from general to earmarked reserves reflecting the IJB's commitment at its March 2023 meeting to support the purchase of digital alarms.

2 RECOMMENDATIONS

2.1 Members are asked to:

i) Note the month 5 position and the work being undertaken by the partners to recover the IJB's financial position in 22/23.

ii) Note the update on the financial planning process.

iii) Note the update on the preparation of the IJB's 22/23 Annual Accounts

iv) Agree to the transfer of the funds to support the transfer of analogue to digital alarms from the IJB's general to earmarked reserves.

3 BACKGROUND

3.1 The IJB's Quarter 1 financial forecast was presented to the IJB at its September 2023 meeting. This showed a projected overspend for the financial year 2023/24 of £8.5m. The IJB has since received the financial monitoring reports from its partners for August 2023 (month 5). This shows :-

East Lothian IJB - Month 5 position

	Budget £m	Actual £m	Under/ (over) spend £m	Revised out-turn £m
Core	34.69	34.861	-0.171	-0.703
Hosted	6.8	6.818	-0.018	0.001
Set Aside	9.8	10.528	-0.728	-2.106
Health	51.29	52.207	-0.917	-2.808
Social Care	24.935	22.682	-2.253	-3.971
Total	76.225	74.889	-3.170	-6.779

The detail of these reports are attached as appendices.

3.2 It can be seen from the above that the year-end forecast (the out- turn position) has improved from an overspend of £8.5m from the Q1 review to a projected overspend of c. £6.8m derived from the month 5 position. Although this is an improvement it still indicates a very serious challenge in the current financial year The IJB's Integration Scheme lays out the process to manage in-year financial variances which is, in the first instance, to require the partners to prepare and deliver a recovery plan. This work is on-going and both partners are also preparing a quarter 2 review which will be based on the financial position at month 6. Early indications suggest a continuing improvement although not yet break-even position. As was discussed in the September paper, if NHSiL is able to reach a break-even position in 23/24 then this will allow the health element of the IJB to break-even. Within the social care services, as was discussed in the September paper, further clarity is required on the funding for the settlement of the local authority pay award. That said, in the final instance, any final overspend within the IJB will return to the partners.

3.3 At its meeting in December 2022, the IJB was presented with an outline of its medium term financial plan 2022/23 to 2026/27. This showed

Year	22/23 £m	23/24 £m	24/25 £m	25/26 £m	26/27 £m
Total Income	188.86	180.45	181.55	182.74	183.95
Total Expenditure	188.95	185.20	188.94	193.36	197.92
Gap before savings plans	-0.09	-4.75	-7.39	-10.61	-13.96
% Gap	0.00%	-3.00%	-4.00%	-6.00%	-8.00%

Although this forecast was developed at a relatively high level it can be seen that the current forecast for 2023/24 above (an overspend of c. £6.8m) is significantly worse that the forecast position made in December 2022. The partners are currently developing the budget setting plan and outline financial forecasts for 2024/25 and beyond and the IJB is, in conjunction with this work, developing its own financial plan for future years. Its already clear taking into account financial pressures already in the system - (for example) GP prescribing, a national care uplift estimated at 5.5%, care at home inflation estimated at 3.5%, and pressure from unfunded pay awards that the IJB is now going to have to take significant actions to continue to live within its means in future years. Further work on the financial plan will be reported to the IJB at its next meetings.

3.4 The external audit of the IJB's Annual Accounts is now almost complete and a full report will be brought back to IJB's next meeting asking the IJB to approve its 2022/23 annual accounts.

3.5 At its meeting in March 2023, the IJB agreed to support the Council in its purchase of new digital alarms reflecting the national change-over from analogue to digital throughout the telephone network. The total sum agreed was £740,000 and this was to be funded from the IJB's general reserves between 203/24 and 2024/25 as was described in the Q1 financial forecast paper presented to the IJB in September 2023. The IJB's general reserve stood at £5,030,000 on 31st March 2023 and it is now proposed that £740,000 is transferred from general reserves to earmarked reserves as described above which will reduce the general reserve to £4,290,000. The IJB's reserves policy suggests a balance of at least c. 2% of turnover which is around £4,000,000 – this means that the general reserve is now at its minimum level.

4 ENGAGEMENT

4.1 The IJB makes its papers and reports available on the internet.

4.2 The issues in this report have been discussed with the IJB's partners but do not require wider engagement.

5 POLICY IMPLICATIONS

5.1 There are no new policies arising from this paper.

5.2 The recommendations in this report implement national legislation and regulations on the establishment of IJBs.

6 INTEGRATED IMPACT ASSESSMENT

6.1 The subject of this report does not affect the wellbeing of the community or have a significant impact on equality, the environment or economy.

6.2 The issues in this report do not require an integrated impact assessment.

7 DIRECTIONS

7.1 There is no implication for Direction at this stage.

8 RESOURCE IMPLICATIONS

8.1 Financial – There are no immediate resource implications from this report. Any resource implications from the outcome of the process will be highlighted in a future report if required.

8.2 Personnel – None

8.3 Other – None

9 BACKGROUND PAPERS

9.1 EL IJB Medium Term Financial Plan 2022/23-2026/27, presented to the December 2022 IJB

9.2 Quarter 1 Financial Forecast for 2023/24, presented to the September 2023 IJB

AUTHOR'S NAME	David King
DESIGNATION	Interim Chief Finance Officer
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DATE	October 2023

Appendix 1 – NHS Lothian IJB Month 5 Position
Appendix 2 – East Lothian Council IJB Month 5 position

Appendix 1

	East Lothian IJB - M05 YTD 23/24 - Financial Statement				
	East Lothian IJB Annual Budget '000	East Lothian IJB YTD Budget £'000	East Lothian IJB YTD Actual £'000	East Lothian IJB YTD Variance £'000	East Lothian IJB - M05 23/24 Forecast Variance £'000
NHS Services					
Core	92,606	33,957	34,127	(170)	(703)
Corporate	733	733	734	(1)	(1)
Hosted	14,089	6,816	6,818	(2)	3
Acute	24,571	9,751	10,528	(777)	(2,106)
Grand Total:	**131,999**	**51,257**	**52,207**	**(950)**	**(2,808)**

			East Lothian IJB - M05 YTD 23/24 - Financial Statement				
Status	**Allocation**	**Service**	**East Lothian IJB Annual Budget '000**	**East Lothian IJB YTD Budget £'000**	**East Lothian IJB YTD Actual £'000**	**East Lothian IJB YTD Variance £'000**	**East Lothian IJB - M05 23/24 Forecast Variance £'000**
Delegated	Core	Community Equipment	656	(327)	(327)	0	9
		Community Hospitals	13,313	6,059	5,658	401	1,033
		Complex Care	178	89	89	0	0
		District Nursing	3,335	1,341	1,242	99	210
		General Surgery	1,091	455	428	27	67
		Geriatric Medicine	1,139	434	402	32	51
		GMS	18,862	7,523	7,705	(182)	(386)
		Health Visiting	2,220	991	1,006	(15)	(102)
		Hospital Services	0	3	5	(2)	(9)
		Learning Disabilities	590	216	234	(18)	(11)
		Mental Health	6,533	2,601	2,358	243	149
		Other	171	69	83	(14)	(34)
		PC Management	4,399	(1,800)	(1,883)	83	112
		PC Services	5,802	2,163	2,177	(15)	(308)
		Pharmacy	160	1	15	(14)	23
		Prescribing	21,420	8,791	9,701	(910)	(1,833)
		Reserves	0	0	0	0	0
		Resource Transfer	4,969	2,879	2,874	5	0
		Substance Misuse	245	102	92	10	(46)
		Therapy Services	7,523	2,367	2,266	100	372
	Core Total		**92,606**	**33,957**	**34,127**	**(170)**	**(703)**
	Corporate	Non Consolidated Payment for AfC	733	733	734	(1)	(1)
	Corporate Total		**733**	**733**	**734**	**(1)**	**(1)**
	Hosted	Community Hospitals	132	88	85	3	(0)
		Complex Care	209	83	75	7	16
		Diabetes & Endocrinology	4	2	1	1	1
		Geriatric Medicine	0	0	0	(0)	(0)
		GMS	(2,024)	457	482	(25)	(88)
		Hospices & Palliative Care	625	261	262	(1)	(2)
		Learning Disabilities	1,708	663	681	(18)	(7)
		LUCS	1,564	578	580	(2)	(5)
		Mental Health	2,968	1,337	1,375	(38)	(26)
		Oral Health Services	1,121	297	287	11	23
		Outpatients	15	15	18	(3)	(28)
		PC Services	844	358	379	(21)	(112)
		Pharmacy	70	5	5	(0)	0
		Prescribing	(439)	(93)	10	(103)	(113)
		Psychology Services	1,378	474	484	(10)	(29)
		Public Health	247	70	64	6	4
		Rehabilitation Medicine	1,194	480	413	67	130
		Sexual Health	1,015	393	394	(1)	(2)
		Strategic Services	0	0	0	0	0
		Substance Misuse	680	264	244	21	18
		Therapy Services	1,984	842	813	28	76
		UNPAC	795	242	167	75	150
	Hosted Total		**14,089**	**6,816**	**6,818**	**(2)**	**3**
Delegated Total			**107,428**	**41,506**	**41,680**	**(173)**	**(701)**
Set Aside	Acute	Acute Management	787	331	349	(18)	10
		Cardiology	930	387	385	2	7
		Children Therapies	24	12	10	1	(1)
		Diabetes & Endocrinology	629	205	252	(47)	(212)
		ED & Minor Injuries	3,012	1,231	1,394	(163)	(534)
		Gastroenterology	2,083	858	990	(132)	(407)
		General Medicine	7,374	3,058	3,229	(171)	(429)
		Geriatric Medicine	3,880	1,632	1,715	(82)	(194)
		Infectious Disease	748	(174)	(204)	30	42
		Junior Medical	590	249	291	(42)	(13)
		Outpatients	155	61	53	8	2
		Rehabilitation Medicine	423	172	188	(17)	(43)
		Respiratory Medicine	1,653	712	779	(68)	(171)
		Therapy Services	2,285	1,017	1,096	(79)	(162)
	Acute Total		**24,571**	**9,751**	**10,528**	**(777)**	**(2,106)**
Set Aside Total			**24,571**	**9,751**	**10,528**	**(777)**	**(2,106)**
Grand Total			**131,999**	**51,257**	**52,207**	**(950)**	**(2,808)**

East Lothian Council
Budget Monitoring 2023/24 - Period 5
IJB - Fiona Wilson

Appendix 2

Service	Business Unit	2023/24 Budget (per Letter)	2022/23 Budget (Amended)	Year to Date			Adjusted Forecast
				2023/24 Actual to Date	2023/24 Budget to Date	2023/24 Budget Variance to Date	2023/24 Full Year Forecast Variance After Adjustments
		£'000	£'000	£'000	£'000	£'000	£'000
Health & Social Care	Adult Social Work	28,033	28,044	10,533	9,291	1,242	1,377
Health & Social Care	Acute & Ongoing Care	11,619	11,618	3,636	4,223	-587	-528
Health & Social Care	Rehabilitation	2,211	2,211	911	869	42	9
Health & Social Care	Learning Disability & MH Community services	17,803	17,809	5,959	5,201	758	1,418
Health & Social Care	Head of Operations	3,302	3,302	1,383	675	708	1,837
Health & Social Care	Business & Performance	4,985	4,969	1,980	2,070	-90	-142
HEALTH & SOCIAL CARE TOTAL		**67,953**	**67,953**	**24,402**	**22,329**	**2,073**	**3,971**
Development	Private Sector Housing Grants (PSHG)	256	256	-139	-148	9	0
DEVELOPMENT TOTAL		**256**	**256**	**-139**	**-148**	**9**	**0**
HRA Capital	Disabled Adaptations	1,000	1,000	520	400	120	0
HRA CAPITAL TOTAL		**1,000**	**1,000**	**520**	**400**	**120**	**0**
HRA	Garden Aid - HRA Community Housing (East)	68	68	43	29	14	0
HRA	Garden Aid - HRA Community Housing (Musselburgh)	67	67	41	31	10	0
HRA	Garden Aid - HRA Community Housing (Prestonpans)	49	49	38	22	16	0
HRA	Garden Aid - HRA Community Housing (Tranent)	54	54	30	19	11	0
HRA TOTAL		**238**	**238**	**152**	**101**	**51**	**0**
		69,447	**69,447**	**24,935**	**22,682**	**2,253**	**3,971**

REPORT TO: East Lothian Integration Joint Board

MEETING DATE: 26 October 2023

BY: Chief Officer

5

SUBJECT: East Lothian Dementia Strategy 2023-2028

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1 PURPOSE

1.1 To seek approval of the East Lothian Dementia Strategy 2023-2028 from the Integration Joint Board.

2 RECOMMENDATIONS

2.1 The IJB is asked to:

i. Agree the East Lothian Dementia Strategy 2023-2028.

ii. To note, that an implementation plan will be developed based on the key outcomes and actions contained within the strategy (please refer to section 3.3 and 3.5 for further detail).

3 BACKGROUND

3.1 Since the publication of its first dementia strategy in 2010, the Scottish Government has put an increasing focus on improving dementia services nationally. Rates of dementia among our ageing population are expected to increase significantly over the next 25 years, demanding greater resources from our health and social care services. In 2023, the Scottish Government published their 4th, 10-year, Dementia Strategy with the aim of putting in place a long-term vision for dementia support in Scotland.

3.2 To date East Lothian has not had a dedicated Dementia Strategy, and services for people living with the illness has previously fallen under the remit of Older People's planning. The IJB Strategic Plan 2022-25 outlines improvement of dementia services as one of the Partnership's key strategic delivery priorities. Development of a dedicated East Lothian Dementia Strategy is a major step towards this and provides a clear strategic framework to improve the offer and provision of dementia

services in line with local need. The aims and actions within the strategy also support the following IJB strategic objectives:

- Develop services that are sustainable and proportionate to need.
- Deliver new models of community provision, working collaboratively with communities.
- Focus on prevention and early intervention.
- Enable people to have more choice and control and provide care closer to home.
- Further develop / embed integrated approaches and services.
- Keep people safe from harm.
- Address health inequalities.

3.3 The Strategy takes a human rights-based approach to ensure that the rights of people with dementia remain at the centre of the provision of services. The key outcomes in the strategy have been taken from work done by the Life Changes Trust which were developed by people living with dementia and their carers, and are based on what was most important to them. These include:

- I get the help I need when I need it
- I am empowered to do the things that are important to me
- I am able to be as independent as possible
- I live in a place that suits me and my needs
- I feel safe, listened to, valued and respected

3.4 The Technical Report, which sits behind the strategy, combines a wide range of national and local data to develop a picture of current and projected trends of dementia within East Lothian and is an important tool for use when developing services and implementing the strategy. It will enable the HSCP to provide targeted support where there is greatest need, identifies areas where there are health inequalities, important gaps in current data, and outlines new research on prevention which may help to delay or prevent symptoms of dementia progressing.

3.5 The strategy outlines several key changes to the provision of dementia services in East Lothian. While these remain in line with the Scottish Government 4th Dementia Strategy, the actions have also been identified, through engagement, as areas that people living with Dementia in East Lothian want us to improve, including:

- Extending the provision of post-diagnostic support past the current 1 year offer to the life-time that people have dementia using the 8 pillar model from Alzheimer Scotland for use as

dementia progresses to provide a whole-life approach to dementia care.

- Placing a greater community focus within dementia support such as expansion of the Meeting Centre model, expansion of the day centre offer to include evenings and weekend services, work to improve the range and accessibility of activities on offer for people with dementia, and increasing the offer of Peer Support. This is in line with the current work being taken forward through the Community Transformation Project

- Work to tackle the stigma people with dementia experience following diagnosis through working with local businesses, community partners and the general public through awareness raising and promoting the benefits of Dementia Friendly Communities.

- Implementing a single point of contact to enable people living with dementia and their carers to access information, guidance and support at any point during their dementia journey.

- Improving training and understanding of dementia to HSCP staff, community partners, third sector organisations as well developing more specialised training for care home and hospital staff when supporting people with more advanced dementia. Similarly, training for carers will also be developed to support them to understand how to manage the more challenging aspects of caring for someone with dementia including potential agitation, aggression or behavioural changes.

- Embedding carer support throughout all stages of dementia care in line with the work being done through the East Lothian Carers Strategy, but also focusing on issues specific to people caring for those living with dementia such as emotional support for those facing anticipatory grief, the need for improved advanced care planning and understanding end of life options, support with income maximisation and the need for improvements in the range of respite options locally.

- Focus on preventative work using newly emerging research on the modifiable risk factors that can be amended to potentially prevent or delay symptoms. Actions include working in partnership with national health messaging to promote brain health among people in schools, those in mid-life, or people with Mild Cognitive Impairment, as well as ensuring that those with hearing loss are referred to audiology.

4 ENGAGEMENT

4.1 Stakeholder engagement was a key element of the activity that took place to inform the development of the East Lothian Dementia Strategy.

An external provider (Outside The box) was commissioned to complete community engagement on our behalf over autumn 2023. This was supplemented with feedback from engagement completed for the IJB Strategic Plan and the Planning for an Ageing Population consultation. Additional engagement was also completed with key professionals and care home staff. A full list of all engagement events can be found in Appendix B of the technical report.

4.2 The Draft Strategy was placed on the consultation hub for public consultation from mid-July to end August 2023 and received 82 responses. Of those responding roughly a 3rd were from each of the following: people in a professional capacity; people with experience of someone with dementia in their family or friends; or people who were unpaid carers of someone with dementia. 1:1 sessions with the Dementia Friendly Friendship Groups were also held to seek initial feedback on the draft strategy. The responses have been used to make final changes to the strategy prior to submission to the Strategic Planning Group.

5 POLICY IMPLICATIONS

5.1 The actions within the strategy cut across a number of the Partnership's other strategies and actions plans and there will need to be ongoing collaboration with each of these including: the Carers Strategy, Mental Health, Sensory Impairment, Suicide Prevention, Physical Disabilities, Learning Disabilities, Palliative Care and Primary Care.

6 INTEGRATED IMPACT ASSESSMENT

6.1 The subject of this report has been through an Interim Integrated Impact Assessment process. While no negative impacts were identified, the interim IIA identified that additional work should be done to ensure that people with dementia using Justice Services, Homeless Services and those dealing with Substance Misuse were appropriately included in the strategy. Further consultation was done with these services and relevant actions incorporated into the strategy. A final IIA is still to be completed.

Dementia Strategy interim IIA May 2023 | East Lothian Council

7 DIRECTIONS

7.1 The East Lothian Dementia Strategy is intended to support and assist in the delivery of the IJB Strategic Plan and all of its associated directions.

8 RESOURCE IMPLICATIONS

8.1 Financial – There is no separate budget for dementia within the HSCP and at present spend for this service user group cuts across many budget areas including primary care, pharmacy, older people's budget,

voluntary organisations budget and carers act funding. Current estimated spend on external dementia services is as follows:

Service Area	**Spend 2023-24**
Residential Care Homes (Based on 81% of residents having a diagnosis of dementia) Older People's Budget	£1,446,494 (Estimated based on FY 2022-23)
Nursing Homes (Based on 69% of residents having a diagnosis of dementia) Older People's Budget	£7,928,958 (Estimated based on FY 2022-23)
Day Centres (Based on 60% of attendees having a diagnosis of dementia. Note this includes the current commitment to expand to include a Musselburgh centre) Voluntary Organisations Budget	£756,964
Day Centre Outreach (ased on 60% of attendees having a diagnosis of dementia) Carers Act Funding	£158,400
Alzheimer Scotland D-Café's x 2 (Note a further D'café is funded entirely by the provider) Carers Act Funding	£20,000
Meeting Centre grant Carers Act Funding	£90,000
Alzheimer Scotland Post Diagnostic Support per year (Provides 3.5 FTE link workers) Voluntary Organisation Budget and NHSL funding	£151,333
Total	**£10,552,149**

Note we are not currently able to separate out Care at Home spending for over 65's for those with dementia as ELSHCP do not record people with dementia under a separate service user group. Instead services are purchased under the Older People service user group.

In depth financial modelling would be required to assess accurate costs for implementation, with potential disinvestment in other areas to support these actions. However evidence from the HIS review of the Midlothian Care Co-ordination model shows that with expansion of PDS to include the 8 pillar model resulted in a 17% reduction in health costs for those with dementia in the area and resource costs to the Partnership are significantly lower than those in other Lothian Partnerships[1]

The actions within the strategy that would require the greatest investment would include:

- Expansion of PDS support over the lifetime that people have dementia – Estimated costs are currently being sourced from Midlothian but this would likely require staff at OT/SW/CCW level and costs would be higher than the £151k currently funded to Alzheimer Scotland which funds Band 5 level staff.

- Roll out of the Meeting Centre model to 5 satellite areas – Potentially a further £90K although funding may be able to be sourced from other areas through the development of a partnership approach with the third sector who could potentially level in other funding. There may also be an option to implement a reduced model using the Fife STAND approach for a roving meeting centre to reach other areas on selected days rather than dedicated satellite areas if funding was not available.

- Increase frequency of Dementia Café's - £20,000

- Development of respite options and companionship services

- Expansion of Day Centre Outreach to include evenings and weekends

ELHSCP is waiting to hear from the Scottish Government whether any additional funding will be attached to the implementation of the national 4th Dementia Strategy, and by extension whether any allocations of funding will be made to support implementation of our own local strategy.

Currently, there is no additional internal HSCP funding allocated to implement the East Lothian Dementia Strategy, however, there is a longer term commitment in place to continue the existing 1 year Post Diagnostic Support offer through provision of a 7 year contract. A significant percentage of the Carers Act Funding is allocated towards dementia support. This covers the expansion of the day centre outreach service and the Musselburgh Meeting Centre. Development of respite services is also being taken forward through the Carers Agenda. Some one-off Carers Act funding may be available for use in supporting implementation of the dementia strategy.

There are several areas within the strategy that can be progressed potentially with little or no additional investment including:

[1] 20200930-his-as-midlothian-report-v10.pdf (ihub.scot)

- Development of an information resource/app – The Living Well with Dementia App is free for HSCP's to use and currently being trialled by Inverclyde. This would require internal personnel to develop and work with key partners and local community groups. Accessibility of information for BSL and ethnic minority groups may require translation fees.

- Mental Health Support for people with dementia and their carers – Potential to explore the use of the existing adult mental health and community based services to support people with dementia and the impact on mental health. COEL also currently offers a counselling service for carers which could be expanded to support carers with anticipatory grief.

- Expansion of the PDS service to include the 8 pillar model and to provide support over the lifetime of the strategy would provide additional benefits including:

    - Incorporating conversations/reviews of Anticipatory Care Plans and end of life options

    - Incorporating information on risk factors to aid in prevention of symptoms, although this should also be supplemented by national health messaging

    - Opportunities to link in AHP support/ELRS service into the PDS pathway

    - Promoting the uptake of POA and advocacy services

- Training and awareness for care home/hospital staff – potentially progressed by the Dementia Specialist Improvement Lead/ELCHASE with existing resources

- DFEL has facilitated development of current peer support groups and The Open Arms Carers group within their current funding. There has been no indication additional funding would be required to expand this. An additional benefit of DFEL running the memory course would be facilitation of links between those newly diagnosed and the DFEL Friendship Groups to provide additional peer support after the course has ended.

- DFEL have also previously run a Dementia Friendly Design Project which could be adapted for use within council/community buildings to raise awareness of the benefits of dementia friendly design.

- Awareness raising of the benefits of Dementia Friendly Communities is covered under DFEL's current funding but could be supplemented by an internal communications strategy and by our ongoing work with local area partnerships.

8.2 Personnel – ELHSCP will allocate an officer from within the Planning and Performance team to progress the implementation plan.

8.3 Other – N/A.

9 BACKGROUND PAPERS

9.1 None

Appendices:

The East Lothian Dementia Strategy 2023-28

The East Lothian Dementia Strategy Technical Report

AUTHOR'S NAME	Ashley Hardy
DESIGNATION	Strategic Planning and Commissioning Officer
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DATE	12/10/2023

The East Lothian Dementia Strategy: 2023-2028

Purpose of the strategy

The purpose of the East Lothian Dementia Strategy is to set out a strategic plan to improve dementia services that encompasses all aspects of support from pre-diagnosis to end of life care. It will take a human rights based approach, ensuring that the rights of people with dementia and their carers remain at the heart of our policies and practice. It acknowledges that people with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else.

The impacts of a diagnosis of dementia are wide ranging, not only for the person with dementia but also on their families and carers. Dementia can result in a loss of a sense of identity, security and isolation. In addition to the cognitive changes, dementia also brings with it functional and sensory changes that affect how people with dementia are able to engage and manage in their own environment. The emotional toll for both the person with dementia and their carer is also significant due to the loss of relationships and connections and can result in depression, anxiety and stress. This is often compounded by the lack of awareness and stigmatisation of the illness within the general community.

Yet people with dementia have much to contribute. We have heard through our engagement of the lead roles people with dementia are undertaking, as well as inspiring stories of people with dementia becoming 'dementia activists', of those developing groups and activities, and undertaking peer support to help and advise others in a similar situation. We have also heard of the willingness of communities, businesses and local partners to improve and build on the supports already in place, and to create capacity where there is not. We have taken account of the voices of people with lived experience, and the feedback from our engagement form the basis of the actions laid out in this strategy.

There is much good practice already in place in East Lothian from embedding the principles of the Adults with Incapacity Act which ensures that interventions are to the benefit of the person with dementia, to good conversations taking place to determine the outcomes people with dementia want to achieve. East Lothian HSCP also has a real commitment to commissioning for personal outcomes and this is outlined in our new commissioning strategy.

Significant progress has also been made in developing community capacity and increasing awareness of dementia through the work being done by Dementia Friendly East Lothian, Alzheimer Scotland and other partners. There have also been excellent examples of partnership working between these community, third sector and formal HSCP services. We know that these social and community supports are a vital component in helping to maintain people with dementia at home for longer and to enable them to be active, healthy and engaged. While the integration of Health and Social Care services brings with it opportunities for innovation, we must ensure to link these formal supports around these wider community networks to offer a holistic approach to supporting people with dementia and their carers, and to help change perceptions of their rights and abilities.

What is Dementia

Dementia is not a specific disease, but a group of symptoms that describes a deterioration in cognitive function beyond what might be expected as a usual consequence of aging. It results in an impaired ability to remember, think, or make decisions around everyday activities. It can affect memory, communication, reasoning and judgement as well as visual perception beyond typical age-related changes in vision and is often a progressive disease.

While there are various types of dementia, Alzheimer's disease is the most common, accounting for around 50-75% of cases, with Vascular Dementia being the second most common. Those who experience the brain changes of multiple types of dementia at the same time have mixed dementia.

Although age is the strongest known risk factor for Dementia, it does not exclusively affect older people with early onset dementia (those affected under the age of 65) accounting for around 3.5% of cases of those diagnosed.[1] Research has shown that a reduction in certain life-style risk factors may help prevent cognitive impairment which in turn may help reduce the risk of dementia[2]. These include physical activity, obesity, poor diet, alcohol, diabetes, hearing loss and mid-life stress.

There is often a lack of awareness and understanding of dementia that results in stigmatisation, inequality and barriers to diagnosis and care. Although there is currently no cure for dementia, there are treatments, therapies and supports which can help people to maintain their skills and independence and support themselves and their carers to live well with dementia. There are also preventative measures and lifestyle changes that can be adopted at any age to help potentially delay or prevent the onset of dementia.

COVID 19

COVID-19 has had an unprecedented impact on health and social care services, and the people who use them. Research has shown that the most vulnerable groups, including those who have a diagnosis of dementia have been among the hardest hit during the pandemic[3]. At the time, a diagnosis of dementia was not of itself listed as an increased risk factor for COVID-19, yet what we now know is of the deaths that occurred due to COVID-19 in Scotland 28% of those also had an underlying diagnosis of dementia.[4]

[1] Public Health Scotland
[2] Lancet 2020: Dementia prevention, intervention and care
[3] R Tuijt et al: Life under lockdown and social restrictions – The experiences of people living with dementia and their carers
[4] Scottish Government: Excess deaths from all causes and dementia by setting Scotland 2020-2021

The impact of COVID on residents in care homes, where many have a diagnosis of dementia, was well publicised. Bans on visiting caused significant distress to families and residents, and the use of PPE and masks meant many residents found it difficult to understand and communicate with staff causing greater levels of stress and distress.

Those with dementia in the community were increasingly isolated from the loss of normal routines and services that helped maintain their wellbeing. [5] The closure of day services and loss, or restriction, of care at home services resulted in increased levels of cognitive decline and physical frailty while also negatively impacting mental health.[6]

Unpaid carers who increased their caring role to supplement the loss of formal health and social care services, spoke of the toll on their physical, mental and emotional health.[7] Balancing caring responsibilities in the context of the loss of their own support networks has left many carers at risk of burnout, stress and overwhelm.

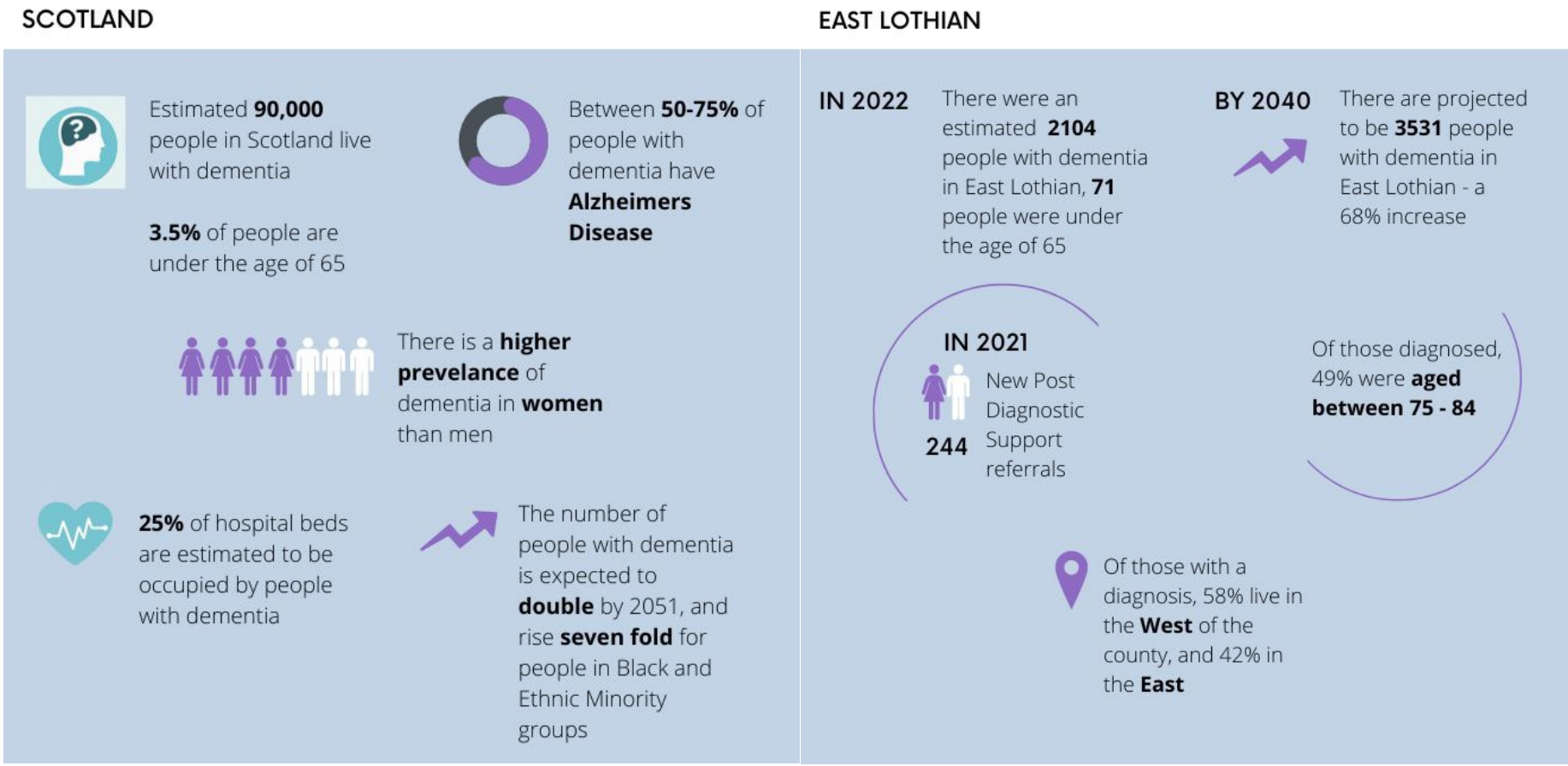
Although restrictions have now lifted and many health and social care services have resumed, ongoing work is needed to continue to support those who have been affected and to support services to get back to pre-pandemic levels.

[5] Alzheimer Scotland. COVID-19: The Hidden Impact

[6] Tuijt et al, 2021. Life Under lockdown and Social Restrictions: Experiences of people living with dementia and their carers during COVID 19.

[7] Carers UK (2020). Caring behind closed doors

Dementia at a glance



Development of the strategy and engagement

"The whole process needs to be evaluated in terms of how people are diagnosed and follow-up support timescales"

Engagement is the cornerstone of strategic planning and offers opportunities for people to participate in policy, service design and decision-making processes in order to deliver better and more responsive services that meet people's preferences and priorities. It also offers greater understanding of where the opportunities are for co-production with partners and service providers.

There is a duty on public bodies to comply with human rights in everything that we do through both the Human Rights Act and the Scotland Act. Delivery of improvement to services must strive to uphold these rights.

In East Lothian much progress has been made with integration and embedding partnership working across our health and social care services. There is a significant amount of expertise across these services that has much to contribute to people with dementia and their carers. We aim to use this strategy to build on these strengths.

A range of communication and engagement events were held over the course of 2022, some in partnership with Outside the Box, who were commissioned to do community engagement on our behalf. Views were sought from people with lived experience and carers, the general public, service providers, community groups and health and social care staff. 660 people attended sessions where dementia was mentioned and 117 were involved in community engagement. We also included feedback from the Life Changes Trust event held for carers of people with dementia in 2018 where 26 carers attended.

We wish to thank all those who took part including those who attended face-to-face meetings, storytelling sessions and who completed online questionnaires. Analysis of national and local data has also informed the development of the strategy and has helped identify gaps, trends and areas of need. All the information collected has been considered and has helped to form the basis of the strategy.

The emerging themes and key findings have been valuable in helping East Lothian HSCP understand and confirm what was important to those living with dementia and their carers.

The clear message was that people with dementia and their carers want to remain as independent as possible for as long as possible, to enjoy daily life, activities and connections as we all do, and for their worth and value as individuals to be recognised and supported at each step of the dementia journey.

Timely diagnosis and accurate, easy to understand information on both the illness and supports available, as well as access to post diagnostic support without delay were commonly mentioned. We were told how improvements in communication through joined up networks, community services and signposting would make it easier for people with dementia to access services and manage their condition, as well as avoiding having to repeat the same information to different staff across the HSCP. Training and awareness raising among HSCP staff and wider community partners would help provide improve understanding of the needs of people with dementia and reduce stigma.

People were impressed by new initiatives, particularly with reference to the Musselburgh Meeting Centre, but wanted further variety and flexibility in activities, noting a desire for existing activities to be inclusive to all to enable people with dementia to remain part of their community. Carers voices were also heard, referring to the need for improved respite and breaks from caring, access to practical and financial support, better information and access to aids and adaptations. Carers also told us of the importance of peer and emotional in supporting their own health and wellbeing.

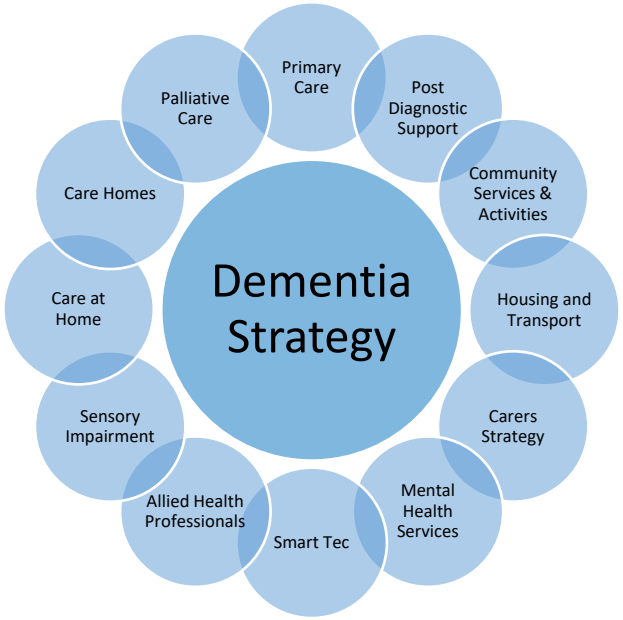
Our Approach

Human rights are basic rights and freedoms that protect us all and are based on dignity, fairness, equality and respect. The East Lothian Dementia Strategy will take a human rights based approach to the provision of our dementia services by embedding the rights outlined in the Charter of Rights for People with Dementia and their Carers in Scotland[8]. The aim is to recognise that people with dementia are citizens first and the framework of support surrounding them should operate with this at its core.

Acknowledgements to: DFEL Musselburgh Friendship Group, Lorna Hill, Sharing a Story CIC, Fringe by the Sea and Year of Storytelling for the use of the graphic

[8] Charter of Rights for People with Dementia and Their Carers in Scotland

The strategy will also use the five main outcomes outlined by the Life Changes Trust which were developed based on contributions from over 100 dementia projects and what their beneficiaries said was most important to them. Each area is interdependent and taken together these priorities contribute to a person-centred, whole life approach.



Our partners

In order to meet the outcomes and actions listed within this strategy, we will continue to engage with a broad range of health, social care, housing, third sector and community services, and in particular key dementia services such as Dementia Friendly East Lothian (DFEL) and Alzheimer Scotland. East Lothian HSCP is also developing a range of other strategies and action plans including planning for Carers, Mental Health, Sensory Impairment, Suicide Prevention, Physical Disabilities, Learning Disabilities, Palliative Care and Primary Care.

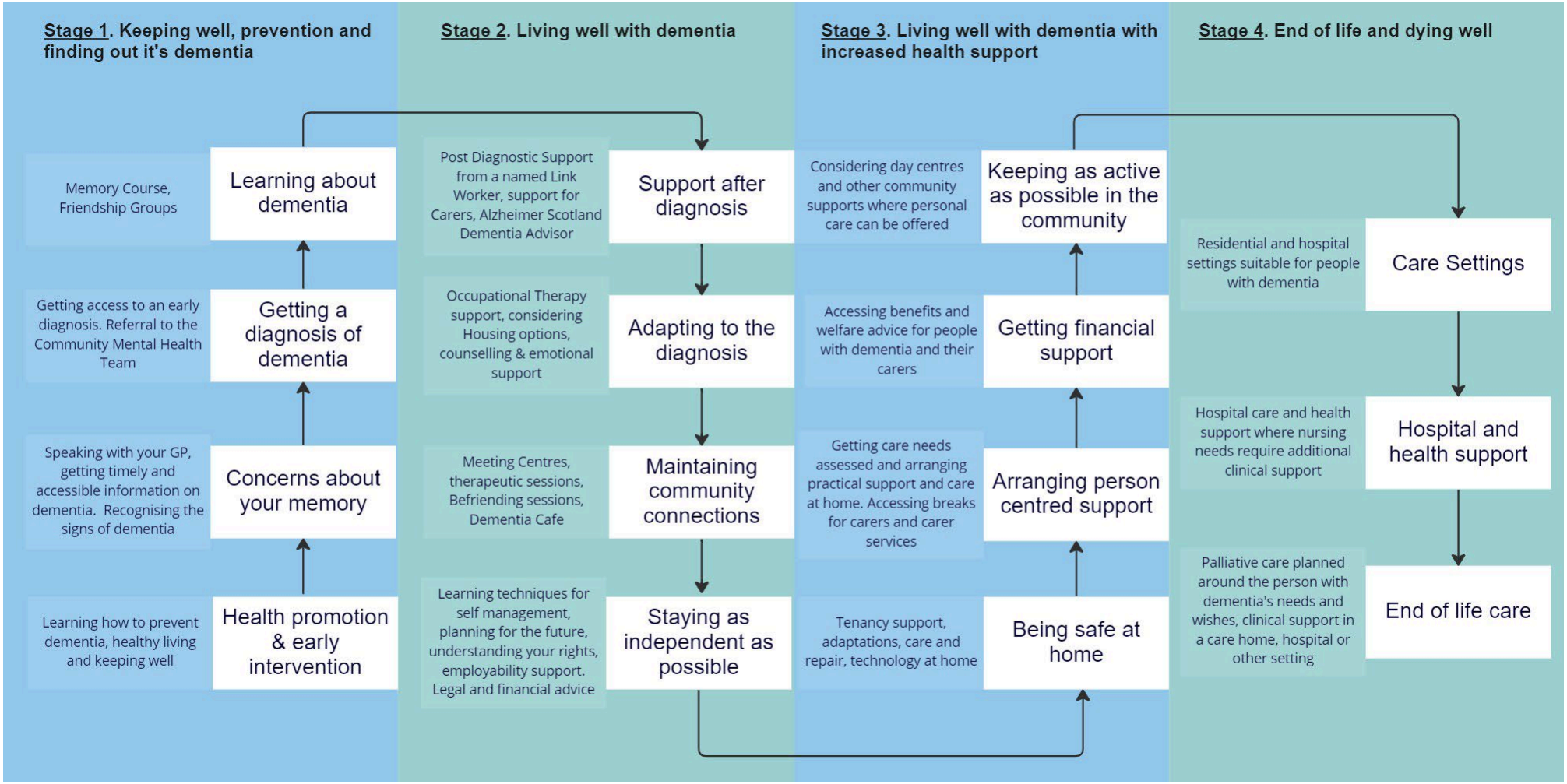
There will be common themes among many of these and interlinking goals. Each strategy will consider the needs of people with dementia and their carers within their own right and outline any specialist support required.

Outcome 1: I get the help I need when I need it

The East Lothian Pathway

Dementia has a number of stages as it progresses, requiring access to different services at different times. Although the pathway below has been developed to outline the range of the services available locally for both people with dementia and their carers, it is not intended to be prescriptive. We recognise that everyone's journey through dementia is unique. People may wish to access services at times other than those suggested and as their individual circumstances require.

People with dementia and their carers have the right to the highest attainable standard of physical and mental health, as well as appropriate levels of care to offer rehabilitation and encouragement. We aim to ensure that everyone with dementia has access to these services to offer them the help they need, when they need it.


Stage 1. Keeping well, prevention and finding out it's dementia
Stage 2. Living well with dementia
Stage 3. Living well with dementia with increased health support
Stage 4. End of life and dying well
Memory Course, Friendship Groups
Learning about dementia
Getting access to an early diagnosis. Referral to the Community Mental Health Team
Getting a diagnosis of dementia
Speaking with your GP, getting timely and accessible information on dementia. Recognising the signs of dementia
Concerns about your memory
Learning how to prevent dementia, healthy living and keeping well
Health promotion & early intervention
Post Diagnostic Support from a named Link Worker, support for Carers, Alzheimer Scotland Dementia Advisor
Support after diagnosis
Occupational Therapy support, considering Housing options, counselling & emotional support
Adapting to the diagnosis
Meeting Centres, therapeutic sessions, Befriending sessions, Dementia Cafe
Maintaining community connections
Learning techniques for self management, planning for the future, understanding your rights, employability support. Legal and financial advice
Staying as independent as possible
Considering day centres and other community supports where personal care can be offered
Keeping as active as possible in the community
Accessing benefits and welfare advice for people with dementia and their carers
Getting financial support
Getting care needs assessed and arranging practical support and care at home. Accessing breaks for carers and carer services
Arranging person centred support
Tenancy support, adaptations, care and repair, technology at home
Being safe at home
Residential and hospital settings suitable for people with dementia
Care Settings
Hospital care and health support where nursing needs require additional clinical support
Hospital and health support
Palliative care planned around the person with dementia's needs and wishes, clinical support in a care home, hospital or other setting
End of life care

Finding Information

"When you don't know, you don't know where to start – we're fumbling in the dark!"

"There is currently the risk of a gap between initial diagnosis and support – very scary for people – whereas with a cancer diagnosis you get a big pack, with dementia you get hardly anything initially"

"It'd be great to have a comprehensive guide to help you through"

People with dementia and their carers have the right to accessible information in order to participate in the decisions that affect them. Knowing where to turn to at each stage and how to access the various supports on offer requires comprehensive information to be available to allow people to manage their own health and wellbeing, and to live well with dementia in a way that best suits their circumstances. Requirements for information will change at key transition points as dementia progresses.

Any information developed must be in an accessible format, bearing in mind that it is common for people with dementia to experience sensory changes as part of their condition.

What we will do

- Review the information provided at point of diagnosis to support people with dementia and their carers to learn more about their condition and explore the options to develop a dementia resource, or app, jointly with the Older People's Mental Health consultant, the Alzheimer Scotland dementia link workers, people with lived experience of dementia and other partners.
- Ensure information is accessible to all including British Sign Language users, minority ethnic groups and young carers who may be caring for a relative with dementia. This includes exploring options via our equalities team to ensure appropriate access to translation services, including those specialising in medical translation.
- Explore opportunities to provide information on preventing or delaying dementia. For those with Mild Cognitive Impairment or a diagnosis of dementia, this will include linking in with national health messaging as well as local initiatives such as access to Alzheimer Scotland brain health survey and use of local resources such as the Meeting Centre. In schools where there is a risk of low educational attainment this should include publicising the Alzheimer Scotland My Amazing Brain programmes to raise awareness of brain health.
- Review and restart the Memory Course for those newly diagnosed with dementia which not only provides valuable information and resources on dementia but offers people newly diagnosed the chance to make peer connections.
- Ensure that people newly diagnosed are linked in to peer support, where people can benefit from information provided by those with lived experience
- Explore how mental health support can be built into the diagnostic pathway to support people to adjust to their diagnosis

- Develop a supplementary guide with the Alzheimer Scotland link workers and other partners detailing wider community support and services at each stage of the dementia journey

Timely Diagnosis

"I started to notice things weren't right with him about 3 years ago…and we are still waiting for a diagnosis"

A timely diagnosis has obvious benefits and is the gateway to receiving quality post-diagnostic support, medication to delay symptoms, as well as information to understand the condition. Diagnostic data shows a new trend in people being referred early with Mild Cognitive Impairment, providing an opportunity to offer health prevention advice to delay symptoms.

There is an increased prevalence of dementia in those with a Learning Disability (LD), particularly among people with Down Syndrome. Although baseline assessments are completed proactively after the age of 35 in those with Down Syndrome, there remains a significant portion of people with an LD diagnosis not known to the Community Learning Disability Team (CLDT).

<u>What we will do:</u>

- Explore whether there should be options developed as to where people can obtain a timely diagnosis, including in community settings.
- Where diagnosis is completed via GP's or psychiatry, a common understanding/checklist should be developed of routes of support available across the community for people with dementia to be referred to.
- Develop a pathway to refer people diagnosed with Mild Cognitive Impairment into awareness raising sessions on helping to prevent or delay symptoms of dementia
- Increase awareness of the benefits of a diagnosis, involving community partners, third sector organisations and statutory services in promoting this
- Consider how we provide, from the available resource, a wider pathway for all people diagnosed with a learning disability to receive an annual health check regardless of whether they are already known to the CLDT service
- Improve data collection on numbers of people diagnosed with dementia and those accessing formal HSCP support to inform future service development. Data on gathering information on ethnicity and diagnosis of type of dementia should also be improved.

Post diagnostic support

"People get a diagnosis and then they are 'on hold'"
"By that point his dementia had advanced and we needed other supports, but we were past the year and got signed off – case closed"
"It would make such a difference if someone could say – if you need anything, just phone and this is the number!"

Quality post diagnostic support helps people to adjust to their diagnosis, both practically and emotionally, providing people with dementia and their carers with the tools and resources they need to live as well and as independently as possible. It also supports people with dementia's right to advanced decision making. In East Lothian, post diagnostic support is delivered over a one year period by a named Alzheimer Scotland Link Worker using their 5 Pillar Model.

What we will do:

- Review the Post Diagnostic Support service using Health Improvement Scotland's Quality Improvement Framework to identify where areas of practice could improve. Ensure that the review is completed with input from people with lived experience.
- Work with our partners to determine the most effective way to integrate the Alzheimer Scotland 8 pillar model to enable each person to receive this for the duration of their time with dementia. Partners will include DFEL, Alzheimer Scotland, Older Adults Mental Health team and others. The review should embed a single point of contact and self-referral into the service. The review should also explore how best to link in local carer services.
- Evaluate the Post Diagnostic Support provided within CLDT to review whether a more formal pathway is required
- Incorporate information on risk factors into post diagnostic support that can help to delay symptoms of progression

Care at home

Many carers reported they were not being supported until they reached crisis point although they try to raise issues as they arise. Earlier intervention would help people with dementia build routines that could help them self-manage for longer and would do much to alleviate carer stress.

What we will do:

- Support the development of a new approach to commissioning care at home services through the new Care at Home Change Board
- Implement the outputs from the work completed with IRISS (Institute for Research and Innovation in Social Services) to re-imagine our approach to Social Work services for adults in East Lothian and how best to implement a more outcome focused and early intervention approach.
- Work with the Lothian Care Academy to roll out dementia training for staff among care at home providers

Hospital Care and Preventing Admission

"Despite my husband having fairly advanced dementia, we had to wait in A & E for 6 hours, he became distressed and had to get a commode…but I was given no assistance or wipes"

There is recognition that hospital admission can have a significant adverse effect for people with dementia. Improving the availability of local hospital services and day clinics at East Lothian Community Hospital and working to prevent admission through the use of intermediate care services will help people with dementia avoid the stress of having to access hospital services out of area.

What we will do:

- Develop good practice on general ELCH wards by rolling out a programme of training to nursing staff to increase knowledge of strategies for managing stress and distress, support development of dedicated care plans, and prevent inappropriate admissions to Oaktrees.
- Ensuring staff within Oaktrees receive more specialist training to enable people with dementia to be assessed locally resulting in fewer transfers of patients to Edinburgh hospitals

Residential and Enhanced Care

The majority of residents in care homes have a diagnosis of dementia. Increasing the current offer of clinical support and specialist training to care home managers and staff will increase understanding and management of complex behaviour and improve outcomes for care home residents.

What we will do:

- Expand the NHS Care Home Team to ensure that all of East Lothian's care homes can receive clinical and education support

- Offer face-to-face stress and distress training to care home staff via the East Lothian Care Home Assessment, Support and Education team (ELCHASE) or the Dementia Specialist Improvement Lead to improve management and understanding of complex behaviour.
- Explore re-establishing OT support within ELCHASE to increase access to wider therapies to support stress and distress behaviour
- Explore development of an enhanced care unit to support those with complex behavioural and neuropsychiatric symptoms.
- Support care homes to provide intergenerational support and awareness raising in the local community to assist them in maintaining community connections

Palliative Care

Timely access to good palliative and end of life care is a national priority and a new Palliative Care Strategy is under development. As improvements in health care are reducing rates of death from other diseases, more people are reaching the advanced stage of dementia. Planning for end of life care is currently embedded in our local care homes through the use of anticipatory care planning, supporting people with dementia's right to advanced decision making.

What we will do:

- Ensure that people with dementia are aware of the options for end of life care in order to develop anticipatory care plans
- Build in reviews of anticipatory care plans within the enhanced post diagnostic support service given that people with dementia's needs and wishes may change over time.

Support for Carers

"Being continually stressed and in a vulnerable state eats away at your ability to speak up"
"You end up with no 'head space' and even the most articulate of people can be reduced to a mess when you are caring for someone 24/7"

Caring for someone can be rewarding, however coping day to day with meeting the needs of a loved one is often challenging and exhausting. The Partnership is currently reviewing the East Lothian Carers Strategy to ensure it remains fit for purpose following COVID, and to ensure carers continue to access the support they need. There are currently significant gaps in access to replacement care to provide carers with a break and East Lothian HSCP is aware of the need to address this.

There are significant crossovers between the dementia and carer's strategies and there will be a need for ongoing links between the two workstreams to ensure that we take into account the specific needs of carers of people with dementia.

What we will do:

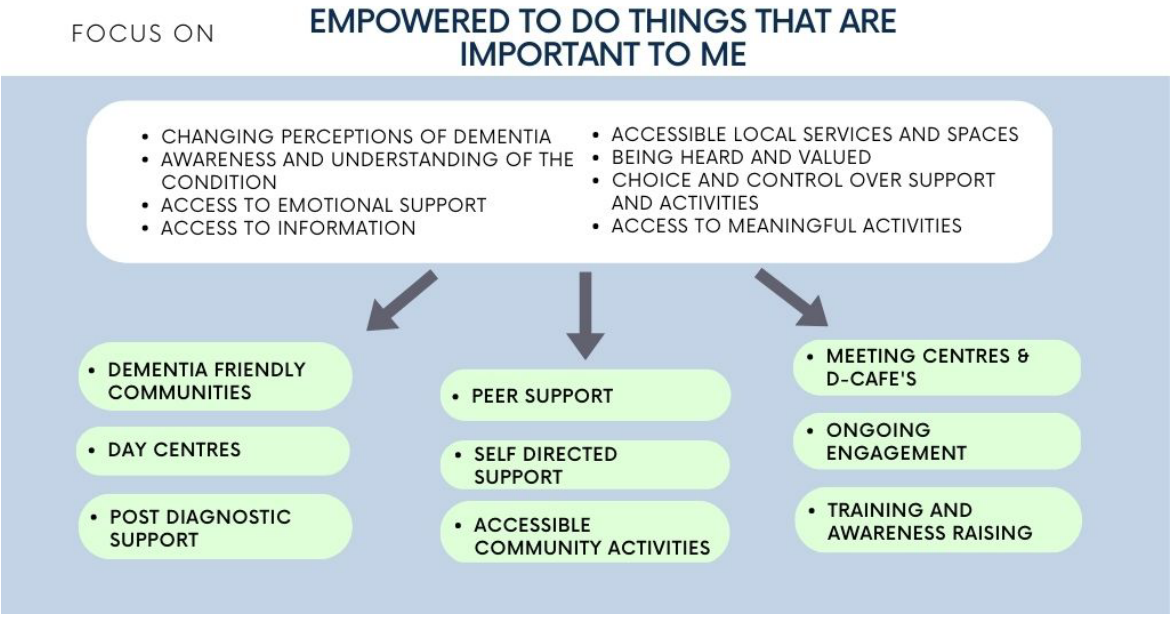
- Explore longer term options to provision of respite services as well as increase the number of respite beds available locally
- Explore options to provide a specialist carer link worker to offer carers of those living with dementia dedicated support
- Develop local training options for carers to support them to understand and manage the condition including managing stress and distress behaviour
- Continue links with the East Lothian Carers Strategy, including the review and simplification of Adult Carer Support Plans
- Develop an increased range of dedicated carer peer support for those caring for someone with dementia
- Ensure Carers of East Lothian's counselling service supports those experiencing anticipatory grief
- Improve the data being gathered around young carers supporting people with a diagnosis of dementia

Outcome 2: I am empowered to do the things that are important to me

Maintaining community connections

People with dementia and their carers have the right to the same recreational, leisure and cultural life in their community that we all do. By far the greatest number of responses received over the course of our engagement was in relation to the desire to access good local connections and activities.

We know the benefits of reducing social isolation. Research also shows that if people make good emotional, social and practical adjustment to dementia early then it is likely they will experience fewer distressing symptoms later and will be able to live at home for longer with a better quality of life. Our aim is to increase the offer and range of community activities across all stages of the dementia pathway to enable people with dementia to remain active, engaged and healthy in older life while also supporting carers to receive a break from caring.



Dementia friendly communities and peer support

"You don't realise how much lack of understanding there is in the community, until you are affected or have a diagnosis"
"We made contact with Alzheimer Scotland and came to the peer support groups. We've found out more information here than from anywhere else and it's good to meet people who can share some of their experiences"
"Although our journeys on this road may be different, we all understand and just 'get it'. We understand that sometimes we just need someone to be there, not to fix anything…but just to let us feel that WE (carers) are also cared for and supported"

Dementia Friendly East Lothian (DFEL) has been vital in supporting the development of East Lothian's 8 dementia friendly communities, working with a range of local organisations and groups to promote the empowerment of people with dementia and striving for local changes to make services accessible.

Such initiatives help support a shift in culture and attitudes and reduce the stigma around dementia. They also help support the rights of people with dementia including their right to maintain maximum independence, full inclusion and participation in all aspects of life, the right to respect and to full access to recreational, leisure and cultural life in their community.

DFEL has also developed a range of local peer support through the Friendship Group model and the Open Arms Carers Group offering chances to build relationships, have fun, address social inclusion and provide information on key links to services. East Lothian HSCP will continue to work in partnership with DFEL and other partners to increase the offer of peer support.

<u>What we will do:</u>

- Work with DFEL to support the roll out of the Friendship Groups to increase access to peer support including increasing access to dedicated peer support for carers of people living with dementia
- Ensure that dementia hubs/groups are accessible to those with a sensory impairment or for people who are deaf with dementia.
- Ensure that peer support groups are included in the "dementia resource" developed for those newly diagnosed
- Explore options for the Friendship Groups to be included in co-producing the Memory Course in partnership with other organisations for people newly diagnosed
- Promote the value of developing Dementia Friendly Communities across all HSCP action plans, working across arts, culture, leisure and recreation; businesses and shops; children, young people and students; community, voluntary, faith groups and organisations as well as transport

Wider community support/services

"Part of the problem is that dementia is a hidden disease which can cause more barriers and stigma – if you look at people with dementia you'd think there was nothing wrong"
"I try to hide it – it keeps the brain going"

Increasing access to local community spaces and services through making environmental changes such as improved signage, hearing and visual modifications will support people with dementia's ability to engage with their local community. Wider access to community activities is especially important for those people who prefer not to join in local groups and people with young onset dementia.

Working with local communities and services in a more collaborative and supportive way to build on community-led solutions and existing capacity will help offer people with dementia greater options to access supports that matter to them, and at the same time do much to combat stigma surrounding the condition. Local services such as libraries are often a first port of call for information in finding out what services are available and pathways to support.

<u>What we will do:</u>

- Raise awareness of the benefits of good design elements within local council buildings in improving access for people with dementia such as that modelled by the Fraser Centre
- Develop a community engagement action plan to offer awareness raising sessions across key community groups and services, and training on how existing activities can be made more inclusive and dementia-friendly.
- Work with Local Area Partnerships and Health and Wellbeing groups to keep the needs of people with dementia on their local agenda.
- Work with local libraries and other community groups to collate and offer quality information on local community services for people with dementia and their carers
- Work with education and local youth groups to increase the range of intergenerational activities including such initiatives as "digital buddies" and Dunbar Diners
- Work with local businesses to improve community understanding with stickers provided to recognise they are a dementia-friendly space.

Dementia Café's and Meeting Centres

Groups such as Alzheimer Scotland's Dementia Café's and Meeting Centres offer many benefits for those with low to moderate levels of dementia including:

- the opportunity to engage with others in a similar situation in a safe, inclusive environment where people can develop social networks and access peer support
- the ability to share experiences and emotional responses to dementia while engaging in social activities tailored to their capacity and interests
- signposting and information on wider groups and activities available locally.
- opportunities to learn more about dementia, self-management tips and practical help
- access to specialist information from key professionals
- spaces where carers can attend in conjunction with the person they care for, providing access to respite or support for themselves

FOCUS ON

MEETING CENTRES

East Lothian Health and Social Care Partnership has funded Dementia Friendly East Lothian to develop the Musselburgh Meeting Centre, East Lothian's first Meeting Centre. Meeting Centres are an innovative form of enhanced community support for people with dementia and their carers.

They operate primarily as a social club with physical, social, creative and cognitive activities chosen by the local members. They are primarily led by people with dementia and their carers and offer greater control in how centres evolve to suit their members needs.

They offer person-centred support and can help connect people to their local communities. Meeting Centres can help support people with dementia and their carers to adjust to change.

They also offer an opportunity to fill the gap identified where monthly dementia café's may not alleviate more significant needs and help build long term resilience.

People told us that access to activities has been fragmented. Although Alzheimer Scotland Dementia Café's now run in 3 locations in East Lothian and people spoke highly of the groups, they would like these to take place more frequently than once a month.

A large portion of East Lothian is rural with a higher portion of people over the age of 70 living in rural areas. There is a need to ensure that access to Meeting Centres is available in rural communities.

<u>What we will do:</u>

- Further expand the Meeting Centre model across the county to include an additional five satellite sites
- Explore the use of the Powys hybrid/pop up model for Meeting Centres in more rural areas
- Build and support partnership working and learning by working together with carers, people with dementia, third sector and social enterprises to make the Meeting Centre and any new satellites sustainable in the long term via a Public Social Partnership

- Explore options to increase the frequency of the Alzheimer Scotland D-café's
- Explore the use of the Musselburgh Meeting Centre as an information and community hub including signposting of those to the centre when newly diagnosed to improve understanding and self-management.
- Explore options to undertake joint commissioning with a neighbouring authority to develop peer support groups for people with young onset dementia where numbers are low

Older People's Day centres

"Make sure that, in all your caring duties, you find time for yourself"

Day centres are a valuable resource for people with more advanced dementia and mobility problems, offering companionship, stimulation and support. They also offer carers a chance to take time for themselves away from caring responsibilities. Day centres provide a person-centred, outcome focused approach through high quality of care and support provided. At least 60% of all day centres users have a diagnosis of dementia and in some centres it is over 90%.

All centres offer a blended model of centre based and outreach community support for older adults with complex needs and their carers to provide options for people to receive 1:1 support in the community and access activities of their choice in a more flexible manner.

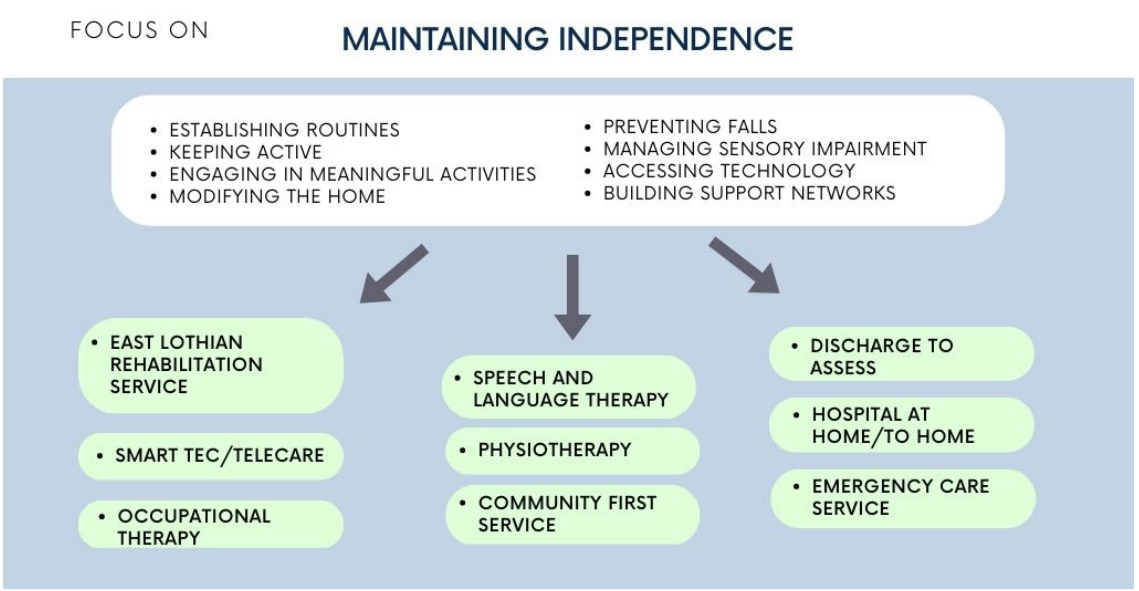
<u>What we will do:</u>

- Review use of the outreach programme, including options to expand this to include evening and weekend support.
- Fund the development of a Musselburgh/Wallyford/Whitecraig Day Service where there is currently a gap in provision and where a high number of people have been identified as living in the community with dementia.
- Explore the use of the Alzheimer Scotland dementia specific day centre model for Musselburgh/Wallyford/Whitecraig area which offers dementia specific therapeutic activities, life story work, and activities tailored to the needs of their attendees to promote independence and engagement.

Outcome 3: I am able to be as independent as possible

Promoting and Maintaining Independence

People with dementia and their carers have the right to maintain maximum independence, social and vocational ability, and full inclusion and participation in all aspects of life. Support to maximise independence relies on a variety of factors.



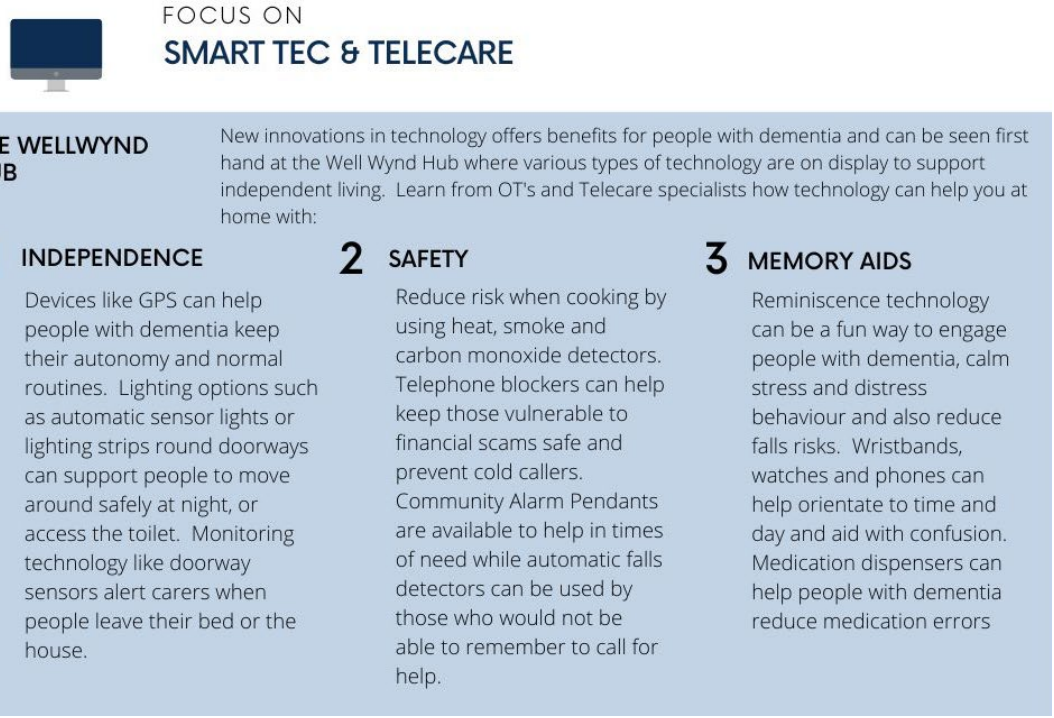
Allied Health Professional (AHP) such as Occupational Therapists, Physiotherapists, Dieticians and Speech and Language Therapists, and SMART Tec/Telecare technicians offer expertise to help people with dementia to live well throughout all stages of the condition, improve hospital and discharge outcomes, and enable people to remain safely and confidently in their own homes and communities for as long as possible.

They can be a point of early detection for functional changes such as difficulties performing everyday tasks, problems with mobility, balance and muscle weakness. They can support signposting for early diagnosis as well as creating strategies to increase or maintain functional performance to help people remain as independent as possible. Offering support both in hospital and community settings, they can help people to regain confidence after a fall, suggest environmental changes or adaptations to prevent future falls, and support people to return home.

Our Digital platform Access to a Better Life in East Lothian offers advice, resources and external links to support self-management. It also enables people to find out how well they are managing with daily living activities using the Life Curve and offers suggestions for improving independence.

What we will do:

- Work with enjoy leisure to offer classes in to improve balance and core issues.
- Expand access to Active and Independent Living Clinics and Smart Tec Clinics across the county, such as that currently offered via the Well Wynd Hub.
- Develop a dedicated AHP strategy
- Ensure the East Lothian Rehabilitation Service is linked into the Post Diagnostic Support pathway
- Promote the use of the Access to a Better Life in East Lothian digital platform and virtual smart house to those newly diagnosed, as well as to care home managers to support environmental changes in care homes
- Promote the use of SMART Tec and Telecare earlier in the dementia pathway to ensure people get the full benefit of technology to maintain independence
- Expand SMART Tec education sessions to local care homes where stress and distress behaviour and falls are more common
- Increase awareness in the community to combat the belief that people with dementia are unable to use technology
- Increase education sessions among HSCP staff to ensure that technology becomes part of their toolkit
- Explore options to use SDS and carer budgets to purchase technology



Community First Service

The Community First Service run by Volunteer Centre East Lothian (VCEL) provides support to people over 50 to access community based services to:

1) Support people to achieve their vision of a good life, use their personal strengths and make a contribution to their community
2) Help communities to be self-supporting

3) Help to transform systems, building bridges and strengthening relationships between citizens, communities and services,
4) Support hospital discharge and prevent readmission.

What we will do:

- Explore expanding the offer to include companionship services to enable carers to have a break, options may include developing 1:1 support or in small groups to encourage connections

Screening for Sensory Impairment

There is growing evidence of a link between sensory impairment and dementia including that hearing impairment increases the risk of cognitive decline.

What we will do:

- Provide information at key points for people to understand the likelihood of increased sensory impairment with dementia and risk to cognitive decline
- Publicise pathways for referrals to audiology in particular to care homes where there are high rates of people with hearing difficulties
- Improve information gathered on vision and hearing loss by social care staff and care home staff prior to admission to a care home
- Work with care home managers to implement simple screening for new residents for impacted wax which can cause pain and hearing loss
- Highlight the benefits of adapting the care home environment for people with sensory impairment including measures such as providing quiet areas for those with hearing difficulties, and appropriate lighting for those with vision loss
- Raise awareness among care home staff of the impact of sensory impairment and the link to Neuropsychiatric symptoms
- Work with care home managers to highlight the importance of regular maintenance of hearing aids and glasses as simple assistive devices.
- Take account of recommendations in the new Scottish Government See/Hear Strategy due 2024.

Meaningful activities and employability support

"I'm very worried about losing my livelihood and what people might say when I have to tell them"

People with dementia have the right to employment and a diagnosis of dementia does not automatically mean a person has to leave work. In addition to the obvious financial benefits, there are other mental and physical health in continuing employment, including the social connections it brings. The Equality Act 2010 obliges employers to provide reasonable work adjustments for people with a disability. Reducing the stigma attached to dementia is an important step in enabling individuals to acknowledge and discuss any problems that they might be having at work because of dementia.

What we will do:

- Raise awareness of the needs of people with dementia within our Local Employability Partnership and Disability and Health subgroup including incorporating this into our local employment strategy
- Work with local volunteering services such as VCEL to support people with dementia to access volunteer opportunities
- Link in employability services to local community groups such as the Meeting Centre, Friendship Groups and peer support groups to raise awareness of available support

Outcome 4: I live in a place that suits me and my needs

Housing

People with dementia have the right to live in dignity and security. The quality of life of someone living with dementia is affected by where and how they live. For many people home is a place of safety, connectedness with neighbours, friends and family, and where their surroundings contributes to a sense of self and identity. We know that people with memory loss also function best in a familiar environment.

What we will do:

- Ensure discussions on housing options are embedded into post diagnostic support and that information on options and tenancy advice is provided in a dementia friendly format.
- Promote the importance of dementia awareness training for housing officers and tenancy support officers, particularly in cases where people with dementia may struggle to maintain tenancies
- Provide advice to Housing to ensure new developments including specialist housing take into account elements of dementia friendly design such as the use of the Kings fund Tool
- Review information provided for those entering sheltered housing and retirement housing and revise into a dementia friendly format

Importance of adaptations

Most people live in mainstream housing, with two thirds in the owner-occupied sector where the vast majority of homes lack even basic accessibility features. Aids, adaptations and assistive technology help people with dementia to live better in all forms of housing and should be considered before making a decision to move home. Aids can also support carers to continue in their role with less risk to their own physical health.

What we will do:

- Explore options to provide information on the benefits of simple adaptations including improved lighting, improved signage such as in sheltered housing, changes to colour schemes and consideration of design and layout to support people's ability to remain independent at home. This could be led by DFEL through their Design Project or jointly via ELHSCP OT's
- Publicise the use of the Access to a Better Life platform to improve awareness and access to physical aids
- Explore the development of step up/step down facilities locally where those being discharged from hospital, or at risk of being admitted, could be appropriately assessed to determine people's abilities and strengths in a homely environment.
- Highlight access to care and repair during post diagnostic support which offers assistance to home owners and private tenant's over 60 to support with help and advice in carrying out repairs, maintenance and adaptations.

Transport

"The Parking around local services is often not accessible, meaning we have to negotiate walking a distance with someone who needs a lot of physical support at times"

Public transport can be a lifeline for people with dementia who are no longer able to drive although can present issues such as recognising places, managing money and difficulties with access. Ensuring local transport facilities are aware of how best to support people with dementia is key to maintaining independence and keeping close links with their community.

What we will do:

- Review the existing RVS service to develop a broader community transport offer including the offer of enhanced support at hospital if travelling alone and simplify processes for referral to the GP Transport scheme
- Work with Transport colleagues to highlight the needs of people with dementia including the benefits of dementia awareness training
- Work with Transport to review the current service provision including the option of a bus stop outside East Lothian Community Hospital to improve access

Financial support

"The sheer volume of what you have to think about means that you often just don't have the headspace to sit and write forms for what you need"

People with dementia and their carers have the right to the same economic rights as we all do, including an adequate standard of living. Having a diagnosis of dementia can place a significant financial burden on families and one that can extend over a significant period of time. For those with young onset

dementia the financial impact may be greater due to earlier loss of employment income and reduced pension entitlements or other ongoing commitments such as child care costs.

What we will do:

- Publicise support available from third sector organisations such as VCEL in providing support to complete benefit forms
- Ensure that carers of people with dementia are aware of the income maximisation support available from Carers of East Lothian's welfare rights worker
- Ensure that all people diagnosed with dementia are referred for income maximisation

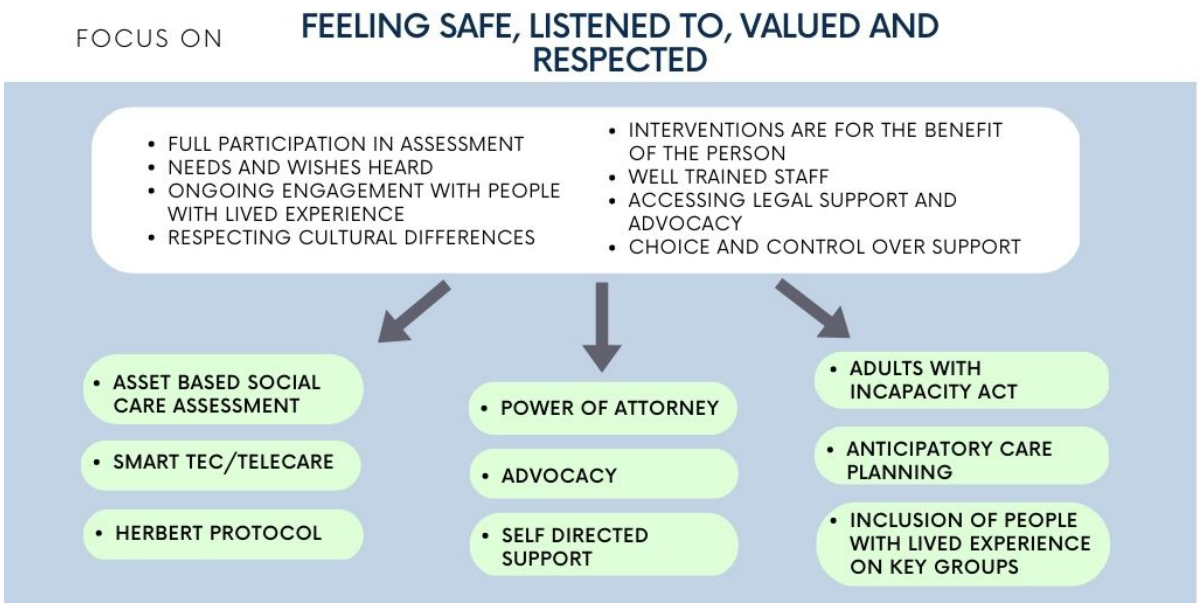
Outcome 5: I feel safe, listened to, valued and respected

Including the voice of people with lived experience

People with dementia not only have the right to have their voices heard and to participate in the formulation and implementation of policies and services that affect their wellbeing, but have much to contribute in leading improvement of services. Enabling people with dementia to participate in key roles will also assist in reducing the stigma around a diagnosis.

What we will do:

- Continue engagement with people with lived experience of dementia to identify gaps in local community resources and support development and on service change and improvement



- Actively promote people with dementia in lead roles in groups such as the Musselburgh Meeting Centre
- Work with DFEL to promote the role of the Meeting Centre as means of accessing training and mentoring in leadership, advocacy and peer to peer skills to build confidence and capacity
- Ensure people with lived experience of dementia are included in key groups such as the Partnership's Change Boards to enable their experience to be incorporated into strategies and policies that affect them

Respecting individual circumstances

People with dementia have the right to respect for their individual circumstances including the right to be free from discrimination based on grounds such as age, disability, gender, race, sexual orientation or religious beliefs. Reducing health inequalities, combating stigma associated with dementia, and embedding a human rights approach to services will help reduce discrimination. This reflects the ethical challenges in the support and protection of people living with dementia, and legislation alone will not be sufficient to ensure the protection of their rights.

What we will do:

- Support awareness-raising campaigns to include education on human rights. Campaigns should also highlight dilemmas related to ethical issues which arise when providing dementia care.
- Ensure that we gather equalities data and understand prevalence rates of those with protected characteristics, including women and black and minority ethnic communities
- Work with LGBT Health and Wellbeing on increasing awareness of the additional challenges faced by LGBTQ+ groups.
- Work with organisations representing Black and Minority Ethnic people on increasing awareness of the additional challenges faced

Access to Independent Advocacy and legal services

People with dementia have the right to access social and legal services to enhance their autonomy, protection and care. As the risk of vulnerability increases as dementia progresses, it is vital that people with dementia and carers have access to independent support to represent their own views where they have difficulty expressing their views, or are unable to do this themselves.

What we will do:

- Complete a review of the current advocacy services to ensure services remain able to meet demand as numbers of people with dementia rise
- Ensure that independent advocacy services are available for people with young onset dementia
- Promote the uptake of power of attorney within the post diagnostic support pathway

- Ensure people with dementia know their rights and how they can get help to make sure they are upheld
- Work with Advocacy services to respond to the experiences of people who feel their rights were not upheld

A knowledgeable and skilled workforce

People with dementia and their carers have the right to services provided by staff who have had appropriate training. Upskilling health and social care staff with appropriate knowledge and understanding about dementia, including the wider sensory and functional impacts of the condition, will ensure that people with dementia and their carers are able to receive person-centred, holistic support and are treated with respect and dignity. We aim to have a more structured approach to dementia training for wider social care staff, as well as those in the third sector and wider community partners who offer signposting and support.

What we will do:

- Make completion of the NHS Education for Scotland Promoting Excellence Framework models at Informed level mandatory for all social care staff and incorporate this into the workforce training plan
- Make Skilled level mandatory for those involved in care planning to improve the quality of support by staff who have direct contact with people with dementia
- Explore options for awareness raising training to be made available for wider housing, community and third sector partners through initiatives such as Alzheimer Scotland's 'Dementia Friends' sessions or use of the Meeting Centre for training.

Full participation in assessment

People with dementia and their carers have the right to full participation in their care needs assessment and in planning, deciding and arranging their support. Building on the good conversations already taking place and shifting to an asset based approach that focuses on building on existing strengths and abilities will help ensure that assessments are structured around outcomes that are important to people with dementia and their carers.

What we will do:

- Review the current assessment format in Adult Social Work to shift to an asset based approach and a personal outcome focus to better incorporate people's abilities and strengths
- Improve information provided on Self-Directed Support including providing examples on ways this can be used flexibly, and in a person-centred way.
- Support Volunteer Centre East Lothian, our Third Sector Interface, to develop and embed approaches to personal outcomes across the third sector.

Herbert Protocol

The Herbert Protocol is a scheme to support the Police and other agencies to locate a missing person with dementia quickly and safely. Increasing awareness of the scheme will help keep people with dementia as independent and as safe as possible.

What we will do:

- Ensure the Herbert Protocol is in use in all East Lothian care homes
- Ensure it is translated into relevant community languages and made accessible to all communities
- Embed information on the benefits of the protocol within post diagnostic support

Appendix A

Policy Context – Relevant policy, drivers and legislation

National Policy

A number of key strategies, policies and legislation have been published over recent years that include aims and measures to support people with dementia and their carers. These include:

- **Scotland's National Dementia Strategy (2017 – 2020).** The third of Scotland's Dementia strategies aims to build on the existing work that has taken place around improving the quality of support for people with dementia and their carers. It outlines key outcomes that it wishes to achieve including:

    - People with dementia have better control over their own care planning
    - Earlier access to quality, person-centred post diagnostic support
    - People with dementia are supported to live at home/in a homely setting as long as they wish
    - Timely access to good palliative and end of life care
    - Better recognition and involvement for carers through all parts of the care journey
    - The right to access good quality, dignified and safe treatment through all care settings
    - More dementia friendly and dementia enabled communities

- **The Carers (Scotland) Act 2016**. Introduces new rights for unpaid carers and new duties for local councils and the NHS to provide support to carers including the duty to offer carers their own support plans, include carers in all hospital discharges and to prepare a local carers strategy

- **Public Bodies (Joint Working) (Scotland) Act 2014**. Sets out the framework for integrating adult health and social care services to ensure consistent provision of quality and sustainable services in order to meet increasing demand.

- **Social Care (Self Directed Support) (Scotland) Act 2013.** Ensures that people have more choice and control of how their services are delivered and the level at which they wish to be involved in managing their own support.

- **The Standards of Care for Dementia in Scotland (2011).** Outlines the range of rights that people with dementia and their carers are entitled to as well as providing guidance to health and social care staff and providers in their care of people with dementia. The Standards are underpinned by the **Charter of Rights for People with Dementia and their Carers in Scotland.**

- **Adults with Incapacity (Scotland) Act 2000.** Provides a framework for safeguarding the welfare and interests of people who lack capacity to make some or all decisions for themselves. It enables carers and others to have legal powers to make welfare, health and financial decisions on their behalf while ensuring that decisions made are of benefit, the least restrictive option and that the person's wishes are taken account of.

- **Age, Home and Community: Strategy for Housing for Scotland's Older People: 2012-2021.** Recognises the importance role of appropriate housing and support in enabling older people to remain at home safely and independently for as long as possible.

- **Connecting People, Connecting Support.** Sets out how Allied Health Professionals (AHP's) in Scotland can improve their support to people living with dementia to enable them to live positive, fulfilling and independent lives for as long as possible.

- **Scottish Government's 2020 Vision for Healthcare in Scotland** is that everyone is able to live longer, healthier lives at home or in homely settings, that integrated health and social care will support prevention and self-management, that hospital admission will only take place when necessary, and people will experience high quality, safe and person-centred care.

- **Palliative and End of Life Care Strategic Framework.** Outlines the key actions to be taken that will allow everyone in Scotland who requires palliative care will have access to it regardless of their diagnosis or setting.

- **Promoting Excellence Framework.** Sets out the knowledge and skills that all health and social services staff should achieve in supporting people with dementia, their families and carers.

- **National Health and Wellbeing Outcomes**. Outlines the shared outcomes that all integrated health and social care services must work towards to ensure services focus on the needs of the individual and enable people to live healthier lives in their community, irrespective of where they live

- **Health and Social Care Standards**. Sets out what everyone can expect from Health and Social Care Services in Scotland, seeking to provide better outcomes, ensure that people are treated with dignity and respect, and that basic human rights to which we are all entitled are upheld.

Local Policy

The East Lothian Integration Joint Board Strategic Plan 2022-25 outlines the key strategic objectives for the East Lothian Health and Social Care Partnership. Although supporting people with dementia has previously been included as a "golden thread" running through many of our ongoing workstreams, the 2022-25 plan puts greater emphasis on improving dementia services in East Lothian by placing it front and centre as one of the main strategic delivery priorities that sit beneath our overarching strategic objectives. Below we describe each objective and its links to dementia care and support.

Develop services that are sustainable and proportionate to need

Developing health and social care services to support the growing East Lothian older population includes a commitment to ensuring high quality care and support is available at the right time and in the right place. The plan emphasises the need to increase and develop the range of intermediate care services to support people to remain at home longer, avoid going into hospital, recover after an illness, or return home from hospital. Building on the existing framework of intermediate care services will enable us to provide care closer to home for people with dementia and their carers, and ensure better outcomes for our population.

Deliver models of community provision, working collaboratively with communities

The Community Transformation Programme has made significant progress in re-designing day services and day opportunities for older people with dementia as well as several other service user groups. The new service model offers opportunities for people to be independent of centre-based services, supporting them to become involved in activities and groups within their local communities.

Future work will focus on greater flexibility by including support at evenings and weekends and by looking at new initiatives such as the Musselburgh Meeting Centre. We will also continue work with community partners to increase options so that people with dementia have greater choice in how their support is delivered.

Focus on prevention and early intervention

Expansion of the range of rehabilitation services is focused on supporting people to retain their independence, increasing community based multi-disciplinary clinics, use of technology enabled care, and health promotion/educational content to help people understand how to manage long term conditions including dementia. People with dementia also experience an increased risk of falls that can result in hospital admission and reduced confidence. Developing a new falls pathway will help to make services more integrated.

Enable people to have more choice and control and provide care closer to home

Greater local healthcare services are a priority for people with dementia and their carers to avoid the stress of travelling to acute hospitals in Edinburgh. Expanding inpatient and outpatient services available at East Lothian Community Hospital will support access to care closer to home.

People with dementia will be able to have greater choice over how and where they receive palliative and end of life care by increasing community based care provided through a range of multi-disciplinary teams, District Nursing and St Columbas hospice that will support both the patient and their family or carers.

Further develop/embed integrated approaches and services

Good progress has been made on delivering integrated health and social care services in East Lothian. For people with dementia and their carers, integrated approaches mean more joined up care, access to a wider variety of specialisms within teams and more streamlined links to other services as needs arise.

Keep people safe from harm

People with dementia and their carers can have concerns around their safety, or the safety of a loved one following a diagnosis and the potential risks as dementia progresses. A diagnosis of dementia does not mean that a person is at risk of harm, or is unable to make decisions about their own safety. The Partnership is committed to taking a "risk-enablement" approach to supporting people, including those living with dementia.

Address health inequalities

The Partnership will continue to develop our understanding of inequalities and how our activities impact them by building our local knowledge using data on population needs, services access and delivery. For people with dementia and their carers, we must improve the range of available data to support this and build on what has already been gathered within our technical report (LINK). This data will then be used to help direct commissioning of services across areas of greatest need.

East Lothian Dementia Strategy – Technical Report

Contents

Introduction

This report examines a range of data including national and local data, as well as policy and research to provide a comprehensive picture and evidence base about the East Lothian population and, specifically, those living with dementia to inform the development of the East Lothian Dementia Strategy and future commissioning plans.

The report:

- Describes the current and projected population changes for East Lothian including the projected change in age profile
- Examines data on mortality, leading causes of death, life expectancy and areas of deprivation
- Describes the current and projected increase in prevalence of dementia in East Lothian and the increased impact on women and those within the BME community
- Examines new research on potentially modifiable risk factors in preventing/delaying dementia
- Reviews numbers of people in East Lothian with a formal diagnosis, the provision of Post Diagnostic Support, and current geographical location of East Lothian residents with a diagnosis to support future service provision.
- Identifies the impact that sensory impairment has on the older population and particularly those with dementia.
- Outlines feedback from the engagement completed to support the development of the dementia strategy and to meet the future needs of people living with dementia in East Lothian.

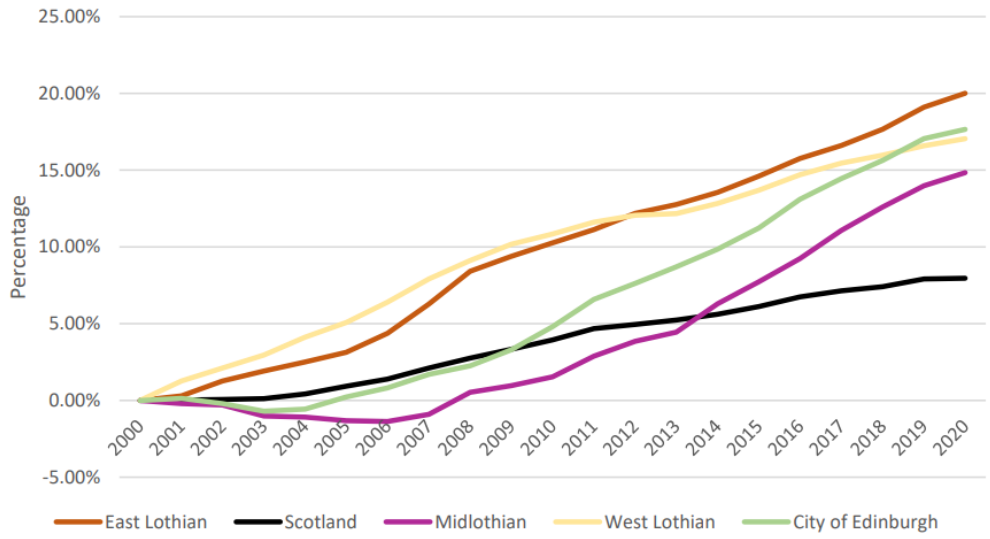
Population of East Lothian

KEY POINTS

- The East Lothian population has grown by 20% since 2000 and at a higher rate than the Scottish population as a whole
- Our population has grown at a higher rate in areas of higher deprivation, specifically within the 1st quintile (most deprived) to the 3rd quintile while the population has decreased in areas of lowest deprivation (4th and 5th quintiles)
- From 2018 to 2043, East Lothian's population is predicted to increase by a further 12.8% reaching a peak of 121,743, and will grow at faster rate than Scotland as a whole
- East Lothian currently has a higher female than male population, although the largest percentage age group in both categories is currently in the middle aged group (aged 45-59)
- While life expectancy is set to increase for both males and females, women in East Lothian continue to have a longer life expectancy than men. By 2043 this projected to increase to 82 years for males and 85 years for females.
- Similar to Scotland as a whole, East Lothian has higher mortality rates among the most deprived areas of the county. The leading cause of death in women in East Lothian is Dementia and Alzheimer's (14.5% of all female deaths) and it is the second leading cause of death in men after heart disease (7.9% of all male deaths)
- The areas of highest deprivation in East Lothian are largely to the west of the county specifically in areas in Musselburgh, Wallyford, Tranent and Prestonpans. There are also pockets of deprivation in Haddington and Dunbar

Current Population Estimates

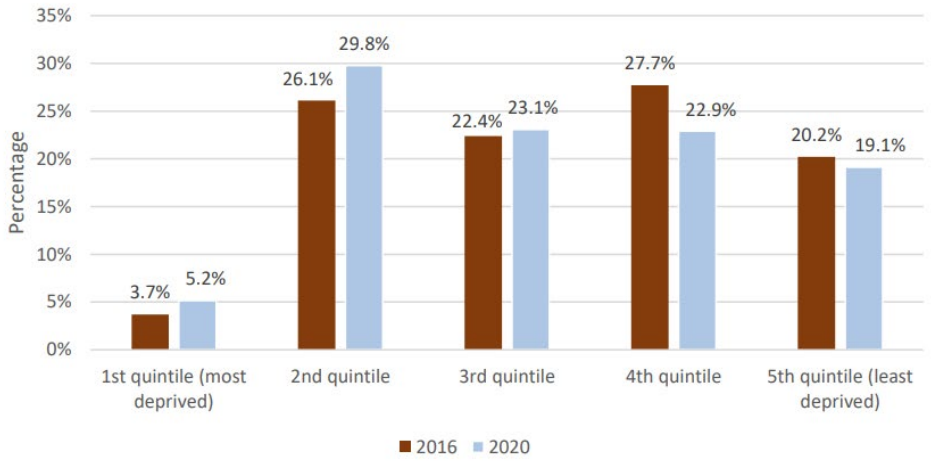
Figure 1. Percentage change of Lothian Partnerships and the Scotland populations



Source: National Records of Scotland, Yearly Percentage Change in Population (Accessed: Jan. 2022)

East Lothian has maintained a higher population increase than Scotland since 2000 and experienced the largest percentage change of Lothian partnerships, with an overall increase of 20% in 20 years.

Figure 2. East Lothian population by SIMD quintile, 2016 & 2020 comparison

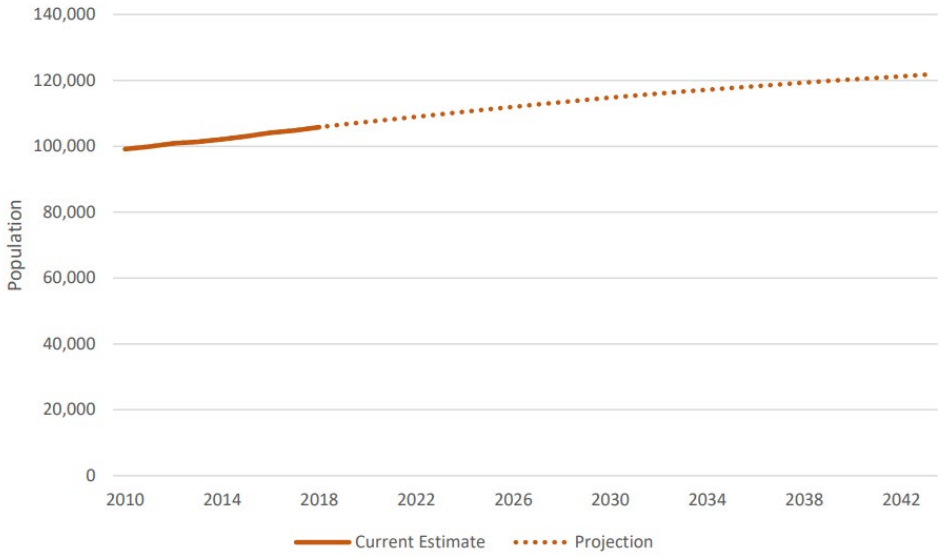


Source: East Lothian by Numbers (Accessed: Jan. 2022)

The Scottish Index of Multiple Deprivation is a measure of deprivation within Scotland across a range of factors. Figure 2 compares the SIMD quintiles (Scottish Index of Multiple Deprivation) breakdown of East Lothian in 2016 and 2020. Quintiles one (most deprived) to three show an increase in percentage since 2016 but the fourth and fifth quintiles have decreased.

Population Projections

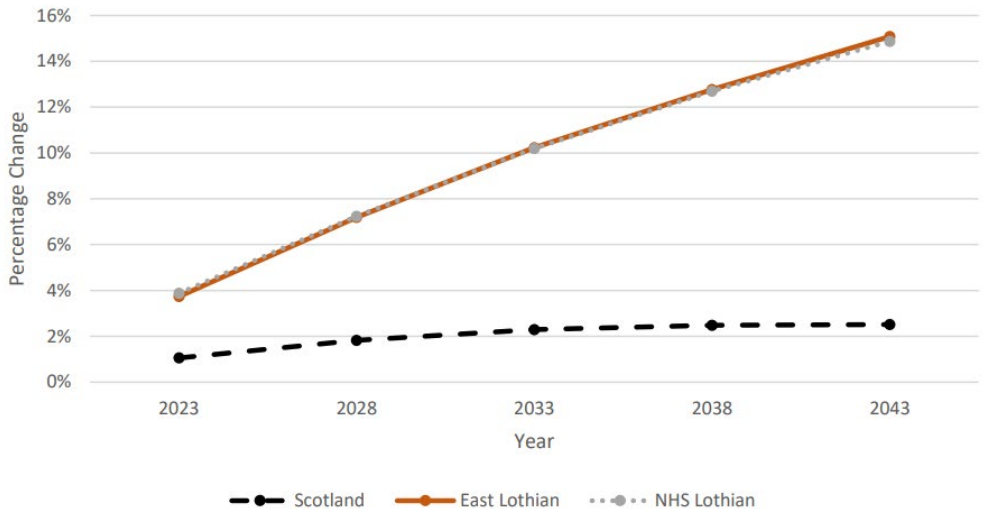
Figure 3. Projected total population for East Lothian (2018-based) 2018 to 2043



Source: National Records of Scotland. Population Projections (Accessed: Jan. 2022)

Figure 3 shows the population projections for East Lothian up to 2043, based on 2018 population estimates. Between 2018 and 2043 the population of East Lothian is predicted to increase by 12.8%, reaching a peak of 121,743 by 2043.

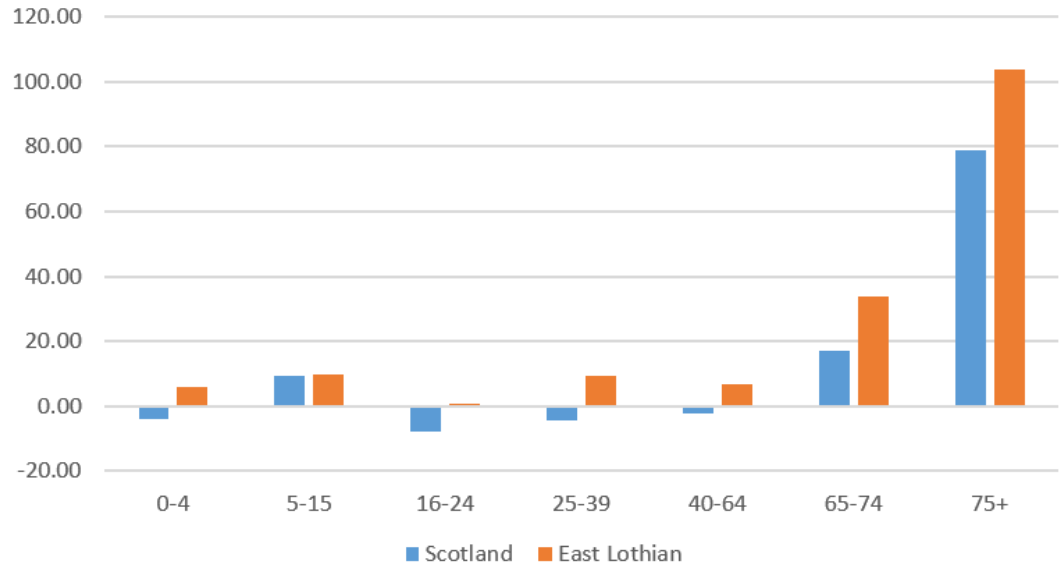
Figure 4. Projected percentage change in population from 2018 within East Lothian, Lothian and Scotland



Source: National Records of Scotland. Population Projections (Accessed: Jan. 2022)

Figure 4 displays the projected percentage change between 2018 and 2043 within East Lothian, Lothian (comprising the areas covered by Edinburgh HSCP, West Lothian HSCP, Midlothian HSCP and East Lothian HSCP) and Scotland populations. Based on these projections, Lothian and East Lothian will see a faster population growth than Scotland. The cumulative changes for East Lothian and Lothian are predicted to differ by 0.2 percentage points by 2043.

Figure 5. Percentage change in population in East Lothian and Scotland by Age, 2016 to 2041

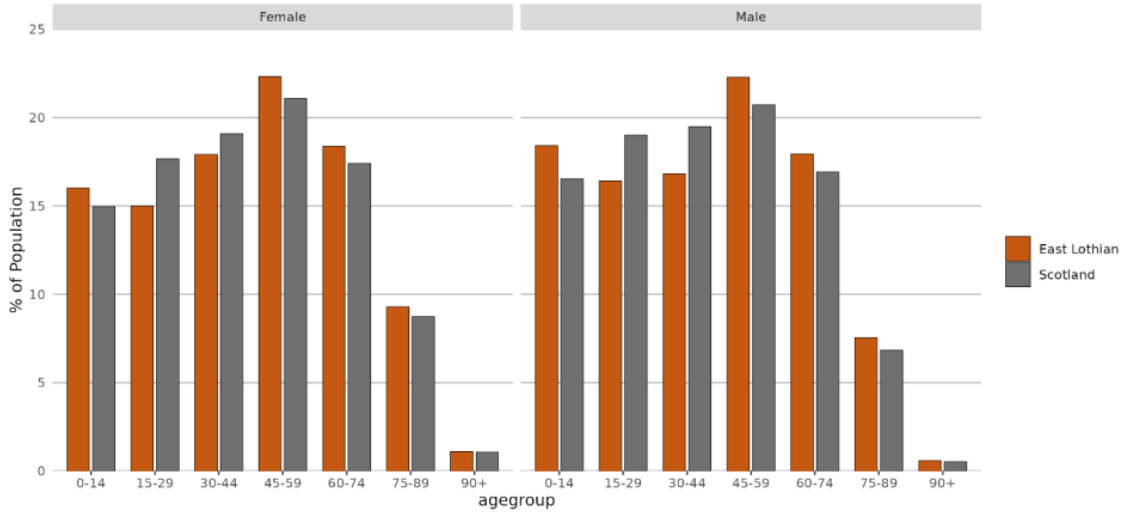


Source: National Records of Scotland. Population Projections 2016-based (Accessed: Jan. 2022)

Figure 5 shows that East Lothian's older population will grow significantly by 2041. The 65-74 age group will grow by around 33.8% while the population over the age of 75 will grow by 103.8%, effectively doubling. The growth in those population age groups is significantly more than in Scotland as a whole.

Population by age and sex

Figure 6. Estimated percentage of population within East Lothian and Scotland by sex and age group in 2020

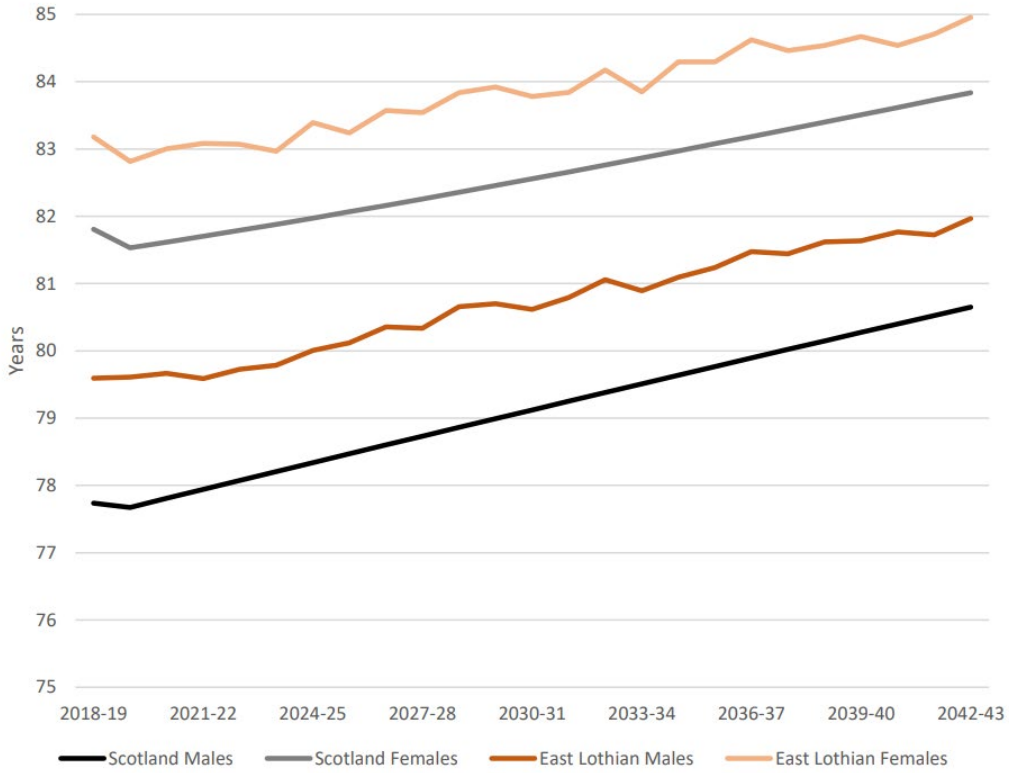


Source: National Records of Scotland. Population Estimates (Accessed: Mar. 2022)

The age profiles separated in Figure 6 show variance in population percentages between geography and sex. The female population in both East Lothian and Scotland has a higher percentage within the middle-aged population, whereas, the male populations has a higher percentage of younger age groups resulting in a more evenly distributed population from ages 0 to 74. The female population percentage is higher than males for both geographies. This partially results from the life expectancy of females being higher than males. The age group 45 to 59 is the largest for both sexes and consists of more than 20% of the population for East Lothian and Scotland.

Life expectancy

Figure 7. Projected life expectancy at birth, principal projection, 2018/19 to 2042/43



Source: National Records of Scotland. Life Expectancy (Accessed: Jan. 2022)

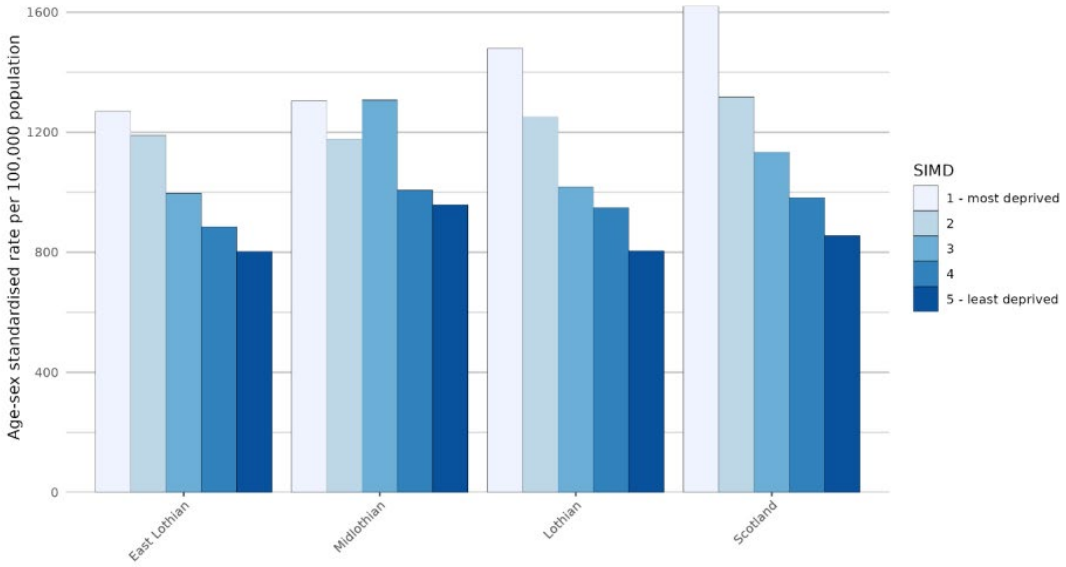
The life expectancy of individuals in the East Lothian and Scottish population is predicted to increase for both sexes up to the latest projected year (2042-43). East Lothian shows more yearly variation than Scotland, likely due to smaller population sizes. Within East Lothian, the life expectancy of males and females is predicted to increase by 2.4 and 1.8 years, respectively by 2042/43. A trend shared by Scotland. Comparing geographies, it is predicted there will be less difference between Scotland and East Lothian life expectancies by 2042-43. There is a predicted decrease of 0.2 (1.4 to 1.2) for females and 0.5 (1.9 to 1.4) for males.

Similar to the outcomes seen in Scotland, East Lothian has a higher life expectancy among females than males

Among females there is a statistically significant difference in average life expectancy between residents of East Lothian (82.9 years) and Scotland (81.0 years). This is also true when looking at the male population, with East Lothian (79.3 years) having a higher average life expectancy than Scotland (76.8 years) again (based on 2018-20 estimates).

Mortality

Figure 8. Mortality rates by geography and SIMD

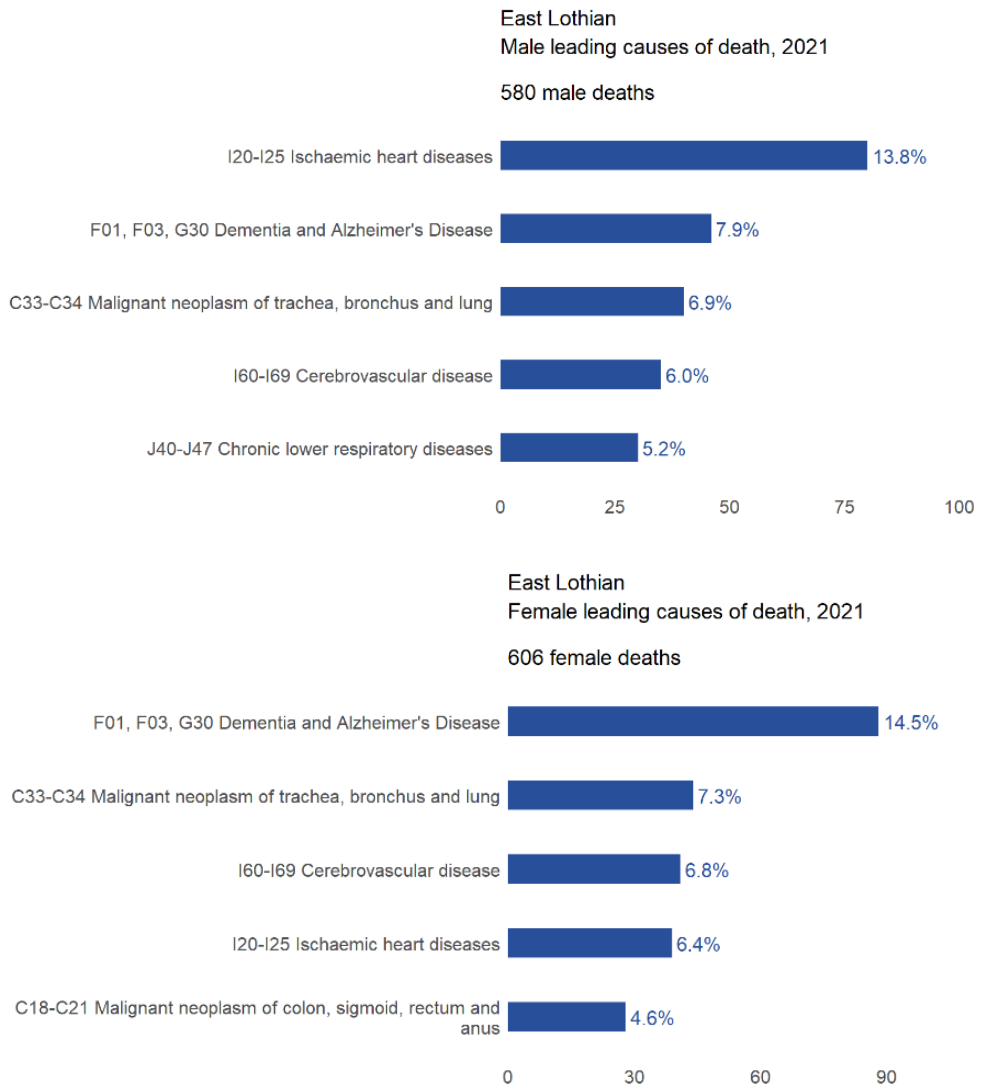


Source: ScotPHO Profiles, (Accessed: Jan. 2022)

Figure 8 separates geographic mortality rates by SIMD. It suggests that mortality in East Lothian, Lothian and Scotland is directly related to deprivation. There is a higher rate of mortality within more deprived data zones for each area.

It also highlights that the mortality rates between the most (SIMD 1) and least (SIMD 5) deprived categories in East Lothian have less difference than Lothian and Scotland categories. A smaller difference in deprivation categories suggests that East Lothian has a more equitable distribution of mortality than the other geographies shown.

Figure 9. Leading cause of death by gender in East Lothian, 2021



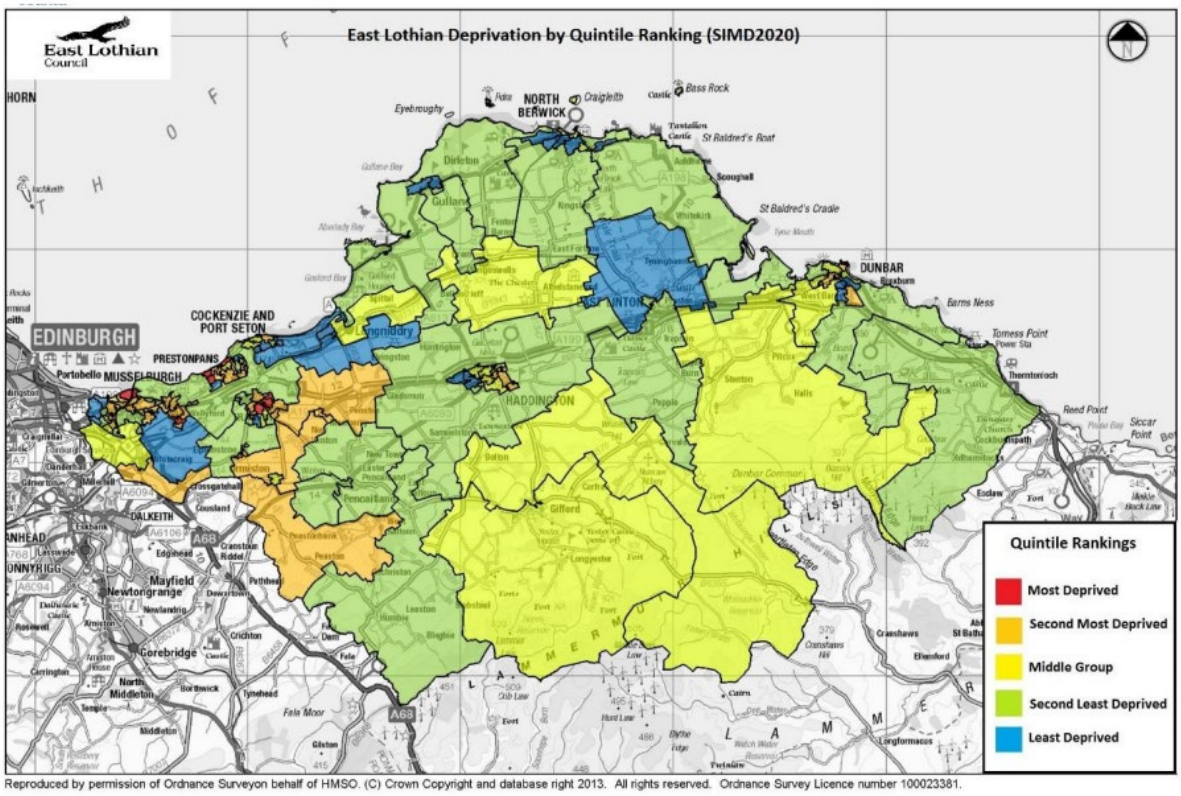
Source: National Records of Scotland, East Lothian Profile, (Accessed: Jan. 2022)

In East Lothian, the leading cause of death for males in 2021 was Ischaemic heart disease (13.8% of all male deaths), followed by Dementia and Alzheimer's (7.9%). In comparison, in Scotland overall, percentage of deaths in males from Dementia and Alzheimer's was lower at 6.2%.

In East Lothian, the leading cause of death for females in 2021 was Dementia and Alzheimer's (14.5% of all female deaths), followed by Lung cancer (7.3%). In comparison, in Scotland overall, percentage of deaths in females from Dementia and Alzheimer's was again lower at 12.8% and remained the leading cause of death in women.

Deprivation

Figure 10. East Lothian deprivation by SIMD quintile



Source: East Lothian by Numbers (Accessed: Feb. 2022)

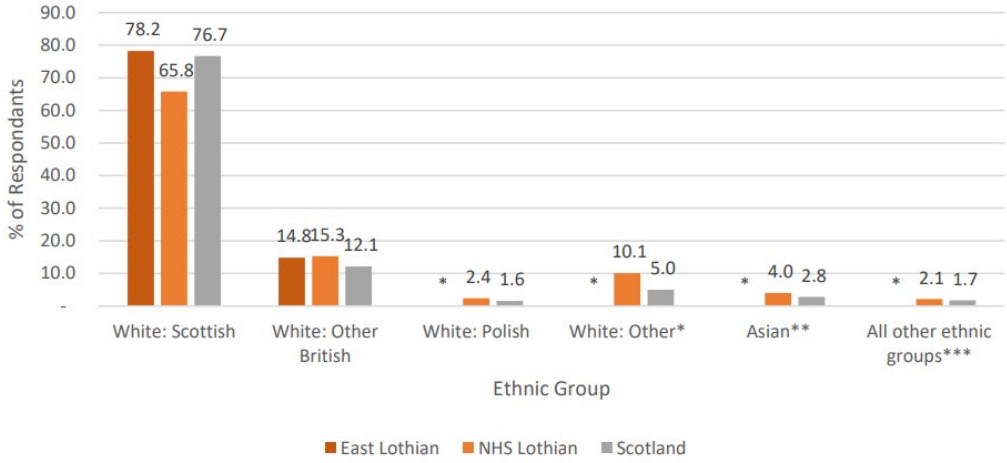
One of the key measurements for deprivation in Scotland is SIMD (Scottish Index of Multiple Deprivation). The index distinguishes the level of deprivation using indicators of income, employment, education, health, access to services, crime, and housing.

East Lothian consists of 6 wards and 132 data zones, of which 8 are in the 20% most deprived of Scotland.

The areas of highest deprivation in East Lothian are largely to the west of the county specifically in areas in Musselburgh, Wallyford, Tranent and Prestonpans. There are also pockets of deprivation in Haddington and Dunbar.

Ethnicity

Figure 11. Percentage of population by response when questioned on their ethnic group



Source: Scottish Survey Core Questions, 2018 (Accessed: Jan. 2022)

'White: Other' includes 'White: Irish', 'White: Gypsy/Traveller' and 'White: Other White Ethnic Group'
** 'Asian' includes the categories Asian, Asian Scottish or Asian British
*** 'All other ethnic groups' includes categories within the 'Mixed or Multiple Ethnic Group', 'African', 'Caribbean or Black', and 'Other Ethnic Group' sections.

The SSCQ survey use of the term Ethnic Group is primarily sourced from the Equality Act (2010). Within this act Ethnic Group is the self or community defined presentation of race. The survey questions focus on the sub-categories of colour, ethnicity, nationality and citizenship which, taken together, delineate Ethnic Group.

Within Figure 11 the largest categories for all geographical areas (East Lothian, Lothian, and Scotland) are White: Scottish and White: Other British.

Note that due to the lower number of responses within East Lothian, the percentage of respondents defining their ethnic group can only be published in the "White: Scottish" and "White: Other British" categories. An asterisk (*) represents a population who were too small to be published publically.

The 2011 Census data however, shows that at the time East Lothian had an increasing range of ethnic minorities residing in the county with the Asian population being the largest ethnic minority group in our area (in 2011 1% of the population). The Polish population had also increased substantially in recent years (0.8% in 2011)[1]

[1] Scotland's Census: East Lothian Overview

Dementia

KEY POINTS

- There are estimated to be 93,000 people with dementia in Scotland, and of those 3200 are estimated to be under the age of 65
- Due to a significant increase in the over 65 population across the UK, rates of dementia are expected to double by 2050, while among the BME population dementia rates are predicted to rise seven-fold by 2051.
- Alzheimer's Disease accounts for the highest proportion of those diagnosed (50-75%) with Vascular Dementia accounting for around 20% of cases.
- Life expectancy following diagnosis varies based on the type of dementia diagnosed but on average life expectancy following diagnosis ranges from 5-10 years.
- Actual incidence of dementia has fallen in many countries with improvements in education, nutrition and health care. New research shows that around 40% of cases of dementia may be preventable or able to be delayed due to changes in modifiable risk factors.
- Around 25% of hospital beds are thought to be occupied by people with dementia although only 1% are estimated to require management within a specialist dementia hospital setting at any one time.
- In 2022, East Lothian has an estimated 2104 people with dementia, projected to rise to 3531 by 2040 (68% increase) while rates of dementia among those under the age of 65 are estimated to remain fairly static.
- Prevalence rates of dementia in East Lothian are higher among women than men in line with national trends. This trend is also confirmed when looking at rates of those with a diagnosis in East Lothian.
- Age has a more pronounced impact on women than men with women having a higher susceptibility to dementia above the age group of 75.
- By 2040, rates of dementia in East Lothian males are projected to peak at the age of 80-84, while East Lothian women will see increasing prevalence for all age groups over the age of 80.
- Of those with a diagnosis, 20% are from the Musselburgh, Wallyford and Whitecraig area and there are higher numbers of people diagnosed generally to the West of the county. Only 5% of those diagnosed live in rural areas.

Dementia in Scotland

In 2017 there were an estimated 93,000 people with dementia in Scotland. Around 65% of these are estimated to be female and 35% are estimated to be male.[2] Using NRS population data for 2017, this equates to around 1.71% of the Scottish population as a whole.[3]

Dementia can affect those as young as 30, although this is extremely rare. Most younger people with dementia are middle aged: in their early 50's and early 60's. The term 'young onset dementia' or 'early onset dementia' refers to people diagnosed with dementia under the age of 65. In Scotland in 2017, there were an estimated 3,200 people under the age of 65 with a diagnosis of dementia. This equates to 0.05% of the Scottish population as a whole.

In 2006-2008 Alzheimer Scotland led the European Collaboration on Dementia with the aim to develop and disseminate evidence-based mental health promotion and Alzheimer's disease

[2] Alzheimer Scotland: Estimated number of people with dementia in Scotland, 2017
[3] National Records of Scotland: Population projections 2016

prevention strategies across Europe. The project also formulated estimates for prevalence which continue to be used as a basis for dementia projections today.

In 2019, Alzheimer Scotland updated their prevalence estimates based on the most up to date studies. The studies show that within the UK there will be an increase in population for the period 2018 and 2050 with a significant increase in the numbers of people aged over 65, and in particular, the over 85 age range which more than doubles between 2018 and 2050. As a result, the overall number of people will dementia in the UK as a whole are expected to double from 1,031,396 to 1,977,399 in 2050. As a percentage of the overall UK population, people with dementia will represent 2.67% in 2050 compared to 1.56% in 2018[4].

Types of Dementia

Although there are many subtypes of dementia the most common ones are Alzheimer's disease, vascular dementia, lewy body dementia, frontotemporal dementia and mixed dementia. Information on the proportions of those with different forms of dementia varies so these should be taken as estimates:

- **Alzheimer's disease** – 50-75 %. This often co-exists with vascular dementia
- **Vascular Dementia** – up to 20%
- **Dementia with Lewy Bodies** – 10-15%
- **Frontotemporal dementia** – 2%

Life Expectancy with dementia

Reliable estimates on life expectancy of people with dementia and Alzheimer's are lacking. Studies recognise that dementia progresses differently for everyone. However it appears that the later in life that a person is diagnosed, the shorter the life expectancy appears to be, conversely if a person is diagnosed earlier then life expectancy can be much longer. There have been cases of people with Alzheimer's Disease at age 65 who have lived for up to 18 years following diagnosis[5]. There also appears to be variances in life expectancy based on the type of dementia that is diagnosed.

Alzheimer Scotland reports the following life expectancy based on dementia type:

- **Alzheimer's**: Around 8-10 years
- **Vascular Dementia**: Around 5 years as a person with Vascular dementia is more likely to die of an increased risk of stroke or heart attack
- **Dementia with Lewy Bodies**: Around 6 years
- **Frontotemporal Dementia**: Around 6-8 years

[4] Alzheimer Europe: Dementia in Europe Yearbook, 2019

[5] Life Expectancy With and Without Dementia: A Population-Based Study of Dementia Burden and Preventive Potential | American Journal of Epidemiology | Oxford Academic (oup.com)

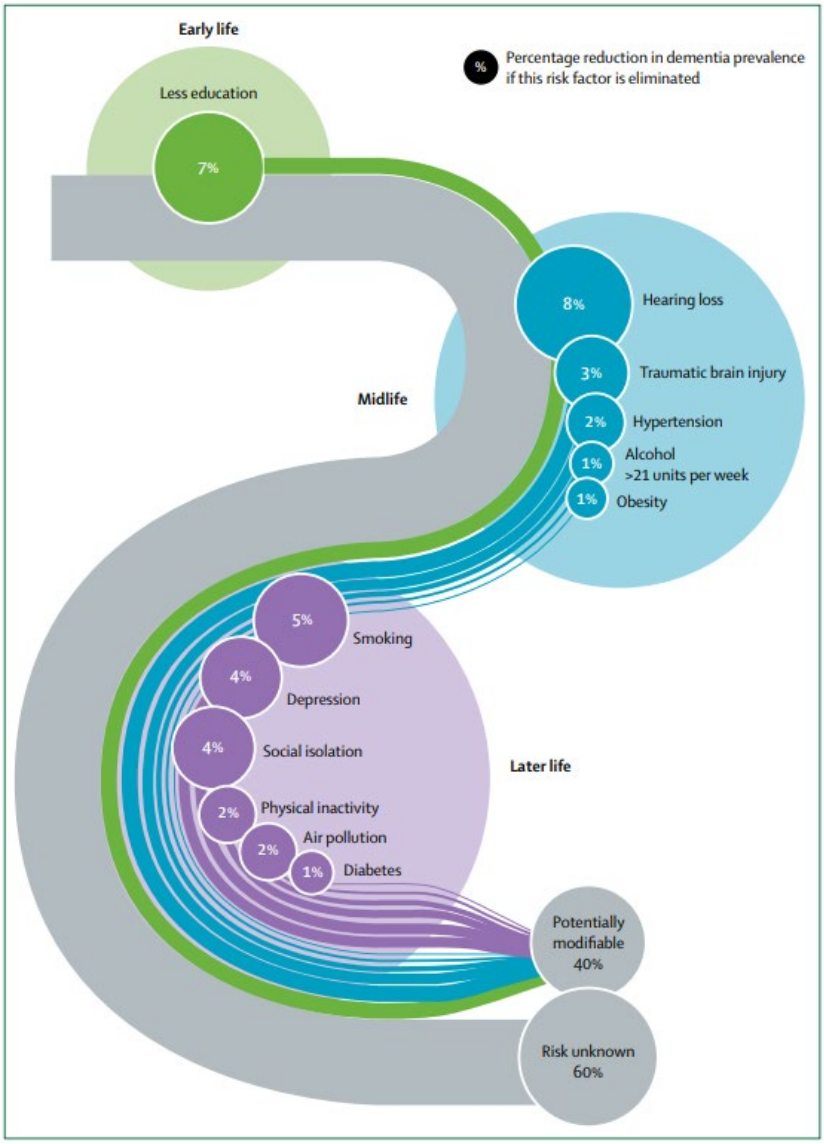
Preventing and delaying Dementia

Although rates of dementia are increasing due to the rising number of older people in the population, the actual incidence of dementia has fallen in many countries, most likely because of improvements in education, nutrition, health care and lifestyle changes.

Growing evidence shows that there are a number of modifiable risk factors that account for up to 40% of worldwide cases of dementia which theoretically if addressed, could be prevented or delayed[6]. These include:

- Minimise diabetes
- Treat hypertension
- Prevent head Injury
- Stop smoking
- Reduce air pollution
- Reduce mid-life obesity
- Maintain frequent exercise
- Reduce occurrence of depression
- Avoid excessive alcohol
- Treat hearing impairment
- Maintain frequent social contact
- Attain high level of education

Figure 12. Population attributable fraction of potentially modifiable risk factors for dementia



Source: Lancet 2020: Dementia prevention, intervention and care

[6] Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - PMC (nih.gov)

In addition to addressing life-style risk factors, social and psychological factors have much to contribute in delaying the progression of dementia. The World Health Organisation states that physical ill-health in older years can be directly impacted by people's physical and social environments and the life-style decisions that arise from that. Improving access to supportive and therapeutic environments such as those offering peer and community supports, cognitive stimulation through participation in social and mental activities as well as support to maintain or build social connection can help people with dementia to remain independent for longer and delay the need to access more specialist resources.

Such environments are also of value to carers, offering peer support and respite as well as connections of their own. Challenging the stigma associated with a diagnosis is also important in helping to provide a supportive environment, as stigma brings with it excess harm and disability notably through impacts such as reduced confidence, low self-esteem and negative impacts on family and social relationships.

Use of hospital services for those with Dementia

It is estimated that approximately 25% of beds in hospitals are occupied by people living with dementia. People with dementia often experience longer hospital stays as well as delays in leaving hospital and reduced independent living as a result.

Alzheimer Scotland estimate that only 1% of people with a diagnosis of dementia will need to be managed within a specialist dementia hospital setting at any one time. This will most likely be due to severe psychological symptoms or a co-morbid mental health condition. The majority of people with dementia can be cared for within a community setting.[7]

Ethnicity and Dementia

Accurate data on black and minority ethnic (BME) people with dementia either at the UK or Scottish level is not available, making it difficult to conduct a needs assessment. Alzheimer Scotland concluded that further research is required to clarify dementia risk within BME groups.

Most recent estimates are that 25,000 people with dementia in the UK are from the black and ethnic minority group.[8] This figure is expected to grow to 171,000 by 2051, a more than seven-fold increase in comparison to the expected doubling in dementia rates for the rest of the population. The increase within the BME groups may be explained by the fact that those migrating to the UK in the 1950's to 1970's are now reaching their 70's and 80's.

Incidence of dementia may also differ from the majority of the population for other reasons such as culturally different dietary and exercise patterns and socio-economic factors such as less formal education, lower income and worse occupational conditions which are often over-represented within BME groups.[9]

The estimated prevalence rates for dementia in the BME community are similar to the general population with the exception of early onset dementia and vascular dementia which have been found to be more prevalent. However, people from the BME community with dementia are less likely to present to services and tend to make contact at a later stage in the illness.

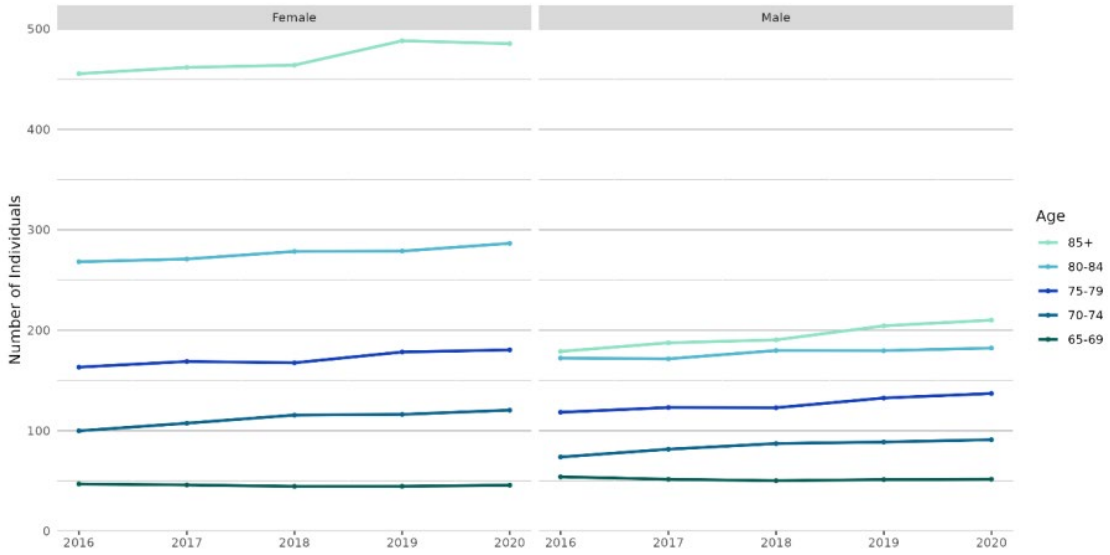
Barriers to seeking help may be:

[7] Transforming Specialist Dementia Hospital Care | Alzheimer Scotland (alzscot.org)
[8] Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities (alzheimers.org.uk)
[9] Pham TM, Petersen I, Walters K, Raine R, Manthorpe J, Mukadam N, Cooper C. Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. Clin Epidemiol. 2018

- **Knowledge related**: Beliefs about dementia including the belief that dementia is a normal part of the ageing process.
- **Society-related**: Including fear of stigmatisation and the view that dementia is a private problem. Cultural expectations that relatives should care for the older person with dementia
- **Health-care Related**: Reluctance to engage with health services and previous experiences of discrimination. Clinicians may also be reluctant to diagnose dementia in BME groups to awareness of cultural bias in standard cognitive tests. Language barriers may also impact diagnosis as well as an understanding of how to access appropriate healthcare.

Prevalence of Dementia in East Lothian

Figure 13. Estimated prevalence of dementia in East Lothian by age, based on 2017 EuroCoDe and Harvey study figures.



Source: Alzheimer's Scotland (Accessed: Mar. 2022)

The prevalence of Dementia within the East Lothian population in Figure 13 was determined by applying 2017 EuroCoDe (European Collaboration on Dementia) and Harvey Study figures to East Lothian population figures (See Appendix A below for further details). The figures are crude estimations and do not account for local variance.

Similar to the national picture, the figure demonstrates higher rates of dementia among women in East Lothian compared to men. This disparity by sex in Dementia prevalence is also seen internationally.

Figure 13 also shows that as an individual's age increases their likelihood of contracting Dementia increases. Age appears to have a more pronounced impact on females than males. In males, there is a consistent and small difference between age groups, whereas the female population shows larger susceptibility to Dementia above the age group 75-79.

The same EuroCoDe and Harvey Study estimates were used across all years, therefore, the yearly increase seen in figure 44 for both male and female populations is due to population increases.

Figure 14. Estimated prevalence of dementia in East Lothian in 2022, based on 2017 EuroCoDe and Harvey study figures.

Age		Men	Women
Under 65	30-59	14	15
	60-64	7	36
		21	**51**
Over 65	65-69	56	48
	70-74	86	120
	75-79	157	199
	80-84	198	299
	85-89	150	316
	Avg 90+	102	301
		749	**1283**

Source: National Records of Scotland, Population Projections (Accessed: Oct. 2022)

Using the East Lothian population data by age and sex for 2022, we can use the EuroCoDe and Harvey prevalence rates to estimate the current number of people in East Lothian living with dementia. In total 2104 people are estimated to currently have dementia in East Lothian. The figures above show the split by gender and age group.

Note that the NRS population data does not provide further break down of projections for the age groups over the age of 90 and therefore an average of the EuroCoDe prevalence rates for the categories of 90-94, 95-99 and 100+ has been used for these age groups.

Projected Prevalence of Dementia in East Lothian

Again, using the EuroCoDe and Harvey Study prevalence figures and applying them to NRS population projections for East Lothian we can estimate the prevalence of dementia in East Lothian by 2040.

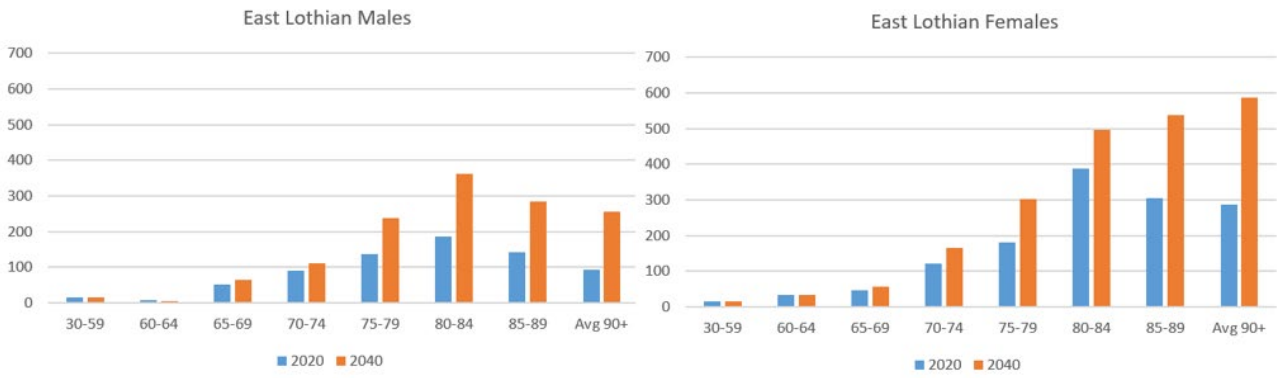
Figure 15. Projected prevalence of dementia in East Lothian in 2040, based on 2017 EuroCoDe and Harvey study figures.

Age		Men	Women
Under 65	30-59	14	16
	60-64	6	33
		20	**49**
Over 65	65-69	64	56
	70-74	112	164
	75-79	238	302
	80-84	361	497
	85-89	285	538
	Avg 90+	257	588
		1317	**2145**

Source: National Records of Scotland, Population Projections (Accessed: Oct. 2022)

By 2040 there will be approximately 3531 people with dementia in East Lothian, this represents an increase of nearly 68% since 2022 (see Figure 14). In contrast to the population over the age of 65, numbers of those with early onset dementia are projected to remain fairly static: 69 of these will be under the age of 65 in 2040 compared to 71 in 2022.

Figure 16. Projected prevalence of Dementia in East Lothian by age and gender from 2020 to 2040, based on 2017 EuroCoDe and Harvey study figures.



Source: National Records of Scotland, Population Projections 2016 (Accessed: Oct. 2022)

Figure 16 shows that in line with the national picture there will continue to be more women than men with dementia in East Lothian in almost all age groups other than the age groups of 65-69.

In contrast to Figure 13 where between 2016 and 2020 there was a consistent but small difference between the age groups for East Lothian males, Figure 16 shows that by 2040 there will be a larger susceptibility to dementia for men between the ages of 80-84.

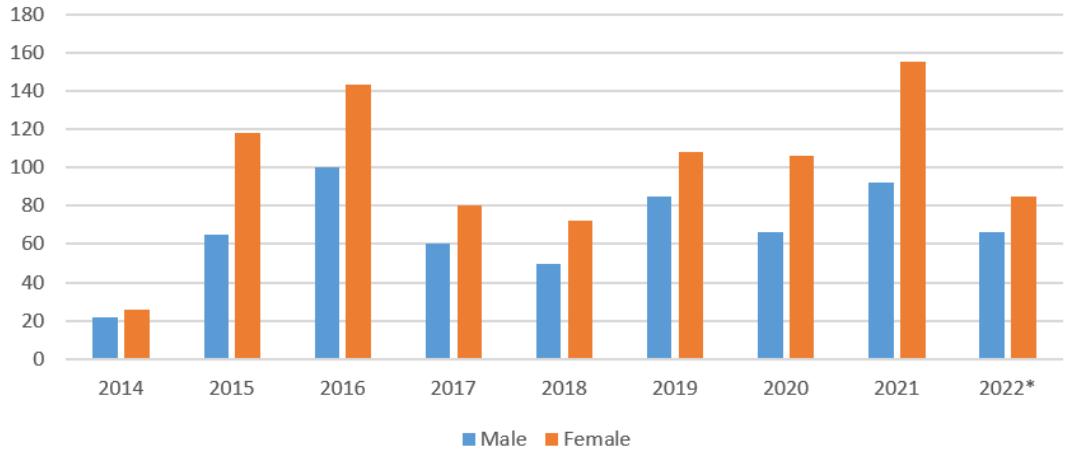
For East Lothian females in 2020, prevalence rates peaked at ages 80-84 and declined in the age range 85 and above. However, by 2040 due to population growth, change in population profile, and longer life expectancy, prevalence of dementia will continue to rise in the age groups of 85 and above in contrast to the male population where dementia rates fall in the over 85 category. Note that NRS population projections show that by 2040 there are estimated to be double the number of women in East Lothian over the age of 90 than men.

Actual Diagnosis Rates in East Lothian

In Scotland, when a person is diagnosed with dementia, a HEAT (Health Improvement, Efficiency, Access and Treatment Targets) Questionnaire is completed and remains open until such time as Post Diagnostic Support has been completed or declined. The data from the HEAT Questionnaires for East Lothian is collated by the NHS Lothian Mental Health Analytics Team and has provided the basis for rates of actual diagnosis in East Lothian.

The Mental Health Analytics Team is part of the wider Lothian Analytics team and provides data relating to mental health services in Lothian including information on demand, capacity modelling and submission to national data sets. These statistics first began to be collected in January 2014 and have been collated until October 2022.

Figure 17. Number of people diagnosed with Dementia in East Lothian by gender, Jan 2014 – Oct 2022



**Data until October 2022* *Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]*

The total number of East Lothian residents diagnosed with dementia between January 2014 and October 2022 is 1499. Data begins to be more consistently collected from 2015 onwards. Using data for the full years from 2015 to 2021, the average number of people diagnosed per year is 185.

In line with national trends, Figure 17 also shows higher numbers of women were diagnosed with dementia in East Lothian for each year since data collection began. There were 893 women compared to 606 men diagnosed with dementia between 2014 and 2022 or 59.6% women compared to 40.4% men.

Age at Diagnosis

Figure 18. Number of people diagnosed with Dementia in East Lothian by age, Jan 2014 – Oct 2022

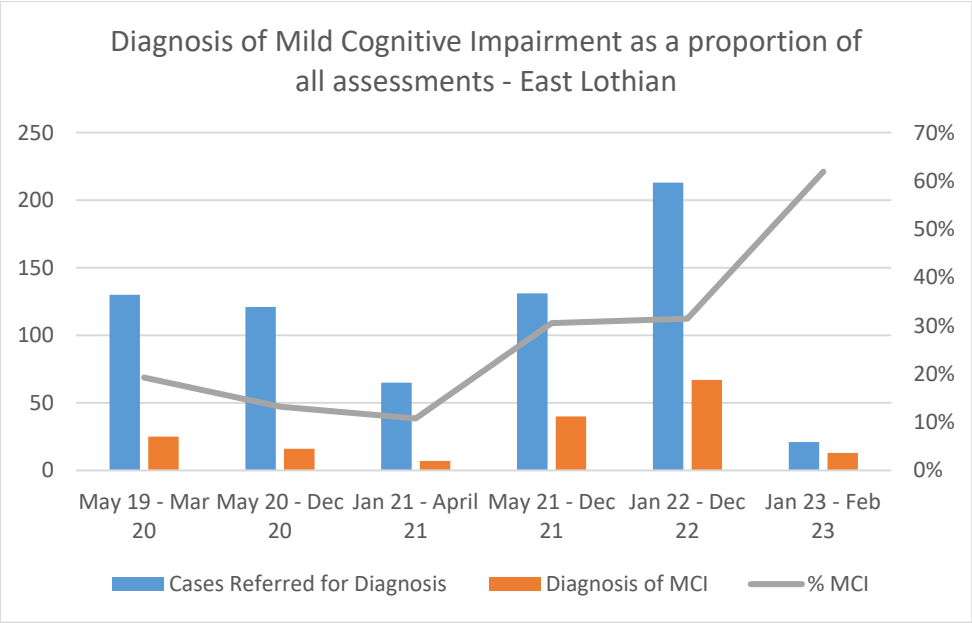
	Age at Diagnosis (Grouped)						
	45-54 yrs	**55-64 yrs**	**65-74 yrs**	**75-84 yrs**	**85-94yrs**	**95 + yrs**	**Total**
No of people Diagnosed by Age Group	**4**	**36**	**257**	**738**	**445**	**19**	**1,499**
% of People	0.3%	2.4%	17.1%	49.2%	29.7%	1.3%	

**Data until October 2022* *Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]*

In East Lothian, of those with a formal diagnosis 1459 (or 97.3%) were over the age of 65 and only 40 (2.7%) were under the age of 65. The youngest person diagnosed with dementia in East Lothian is 47 and the oldest person is 101. The age groups with the highest numbers of people diagnosed were ages 75-84 and 85-94 years old.

Trends in Mild Cognitive Impairment

Figure 19. Rates of those diagnosed with Mild Cognitive Impairment as a percentage of total cases.

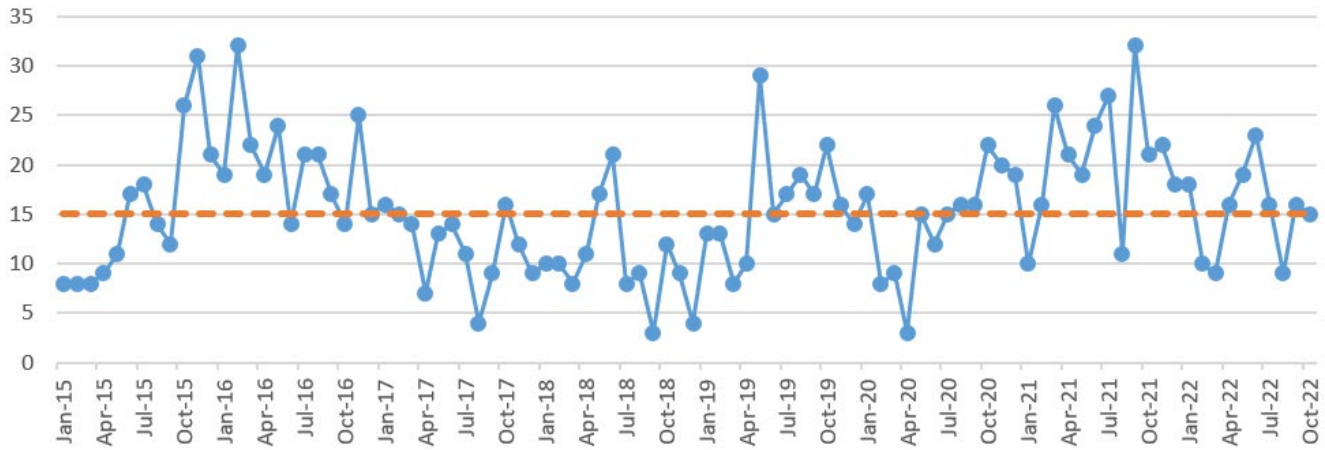


A diagnosis of dementia is made when people reach a certain threshold in the assessment process taking account of medical history, physical examination, testing and assessment of changes in thinking, day-to-day function and behaviour. Below that threshold, people may be diagnosed instead with Mild Cognitive Impairment (MCI) and a certain percentage of those with MCI may then go on to develop dementia.

Data provided by the Consultant at the Memory Clinic shows an increasing trend in the proportion of those diagnosed with MCI rather than dementia. One possibility is that this could demonstrate that GP's are referring people for diagnosis earlier. These statistics do not include people who were re-referred later to be re-assessed where their condition has declined.

East Lothian Post Diagnostic Support register

Figure 20. Number of East Lothian residents added to the Post Diagnostic Support register by month, 2014 – 2022



Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

The data from the Mental Health Analytics team also provides us with the number of people added to the Post Diagnostic Support register by month following diagnosis since data collection began in 2014. Taken over the time period Jan 2014 to October 2022, an average of 15 new diagnoses were made each month.

Provision of Post Diagnostic Support

Figure 21. Post Diagnostic Support Data for East Lothian relating to the LDP Standard

	2018-19*	2019-20	2020-21	2021-22	2022-23**
No referred for PDS	128	188	195	241	160
% of PDS completed for 12 months, or were exempt	35.9%	95.2%	83.3%	75.3%	Incomplete

*Note that 2018-19 there were reporting issues identified

** % data for 2022/23 not yet available as the year is not complete

Source: Public Health Scotland

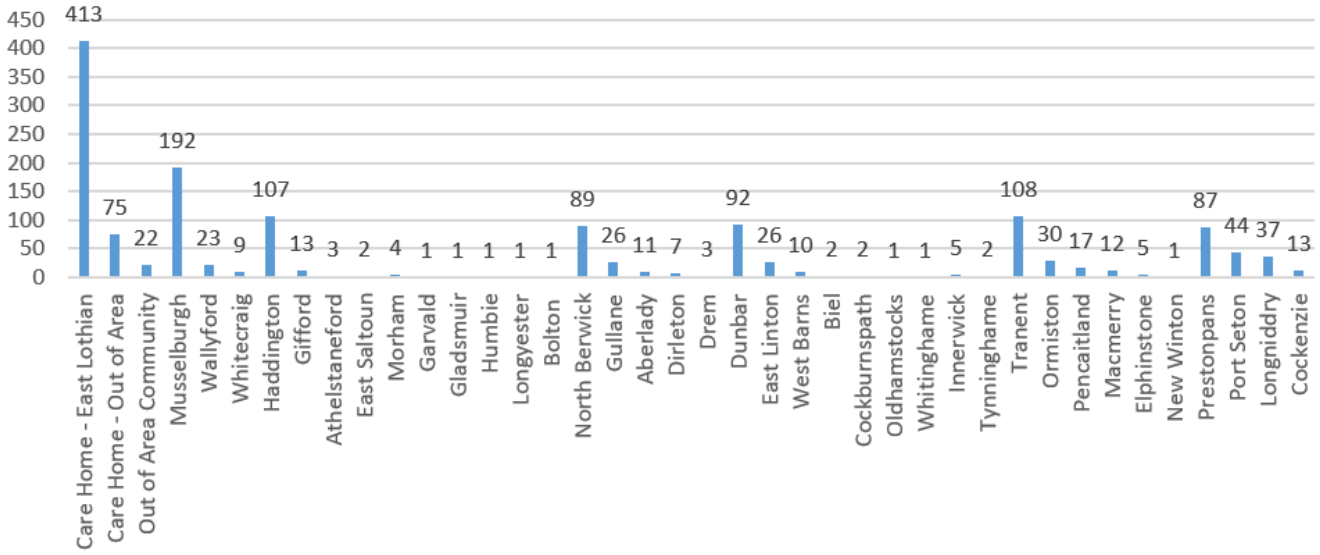
The Scottish Government have set a Local Delivery Standard that all people who are newly diagnosed with dementia receive a minimum of one year Post Diagnostic Support co-ordinated by a named link worker. Data to monitor performance against this standard is collated by Public Health Scotland and shows the percentage of people referred for post diagnostic support who successfully received this support for a minimum of one year. The national average performance against this standard for 2019/20 was 81.3%.

East Lothian's performance against this standard has been variable. Note that there were reporting issues for the data in 2018/19. The variation in the remaining years has been attributed to challenges with recruitment due to the short term nature of the contract with the provider. East Lothian HSCP have now awarded a longer term contract to support this and as a result the number of link workers in post have had a positive effect on reducing the post diagnostic support waiting list from 120 people to 70 as of March 2023, with the expectation that this will reduce further to around 20 people once the new link workers reach a full caseload following training.

Dementia in East Lothian by Geography

The Heat Questionnaire also provides us with data on the current geographical location for East Lothian residents diagnosed since 2014. However, note that as the data is taken live from TRAK, the NHS electronic patient management system, some resident's locations will have changed since their original diagnosis.

Figure 22. Number of East Lothian residents added to the Post Diagnostic Support register by month, 2014 – 2022



Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

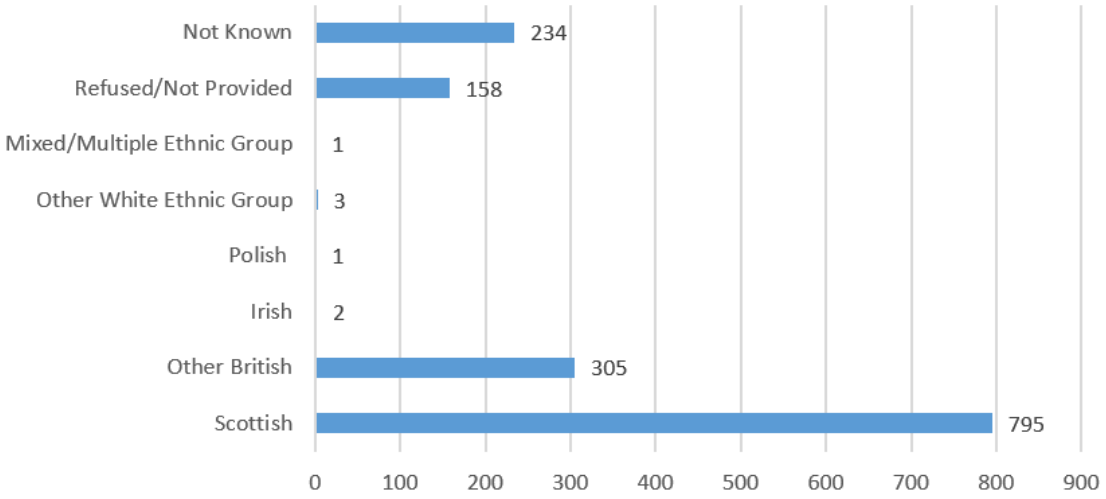
Of the 1499 residents diagnosed since 2014, 488 now reside in a care home either in East Lothian or out of area. A further 22 residents have since left East Lothian but continue to live in the community and the remaining 989 residents (or 65%) diagnosed with dementia continue to live within a community setting within the county. This is in line with the national picture where 61% of people with a diagnosis of dementia live in the community.

Around 95% of people in East Lothian living in the community live within an urban setting and 5% live in more rural settings. Around 22% of those diagnosed live in the Musselburgh, Wallyford and Whitecraig area. Indeed, there are higher numbers of people diagnosed generally to the West of the county (578 people in Musselburgh, Fa'side and Preston/Seton/Gosford wards) compared to the East (411 in Haddington & Lammermuir, North Berwick Coastal and Dunbar & East Linton wards).

Of the 5% living in rural settings, the highest proportion of these residents are within the Haddington and Lammermuir, and Dunbar and East Linton wards. These include the rural towns of Garvald, Gifford, Morham, Humbie, Bolton, Cockburnspath and Innerwick.

Ethnicity of those diagnosed with dementia in East Lothian

Figure 23. Number of people diagnosed with dementia in East Lothian by ethnic group.



Source: NHS Lothian Mental Health Analytics [Accessed Oct 2022]

Unfortunately, the HEAT questionnaire data does not provide sufficient information on the ethnicity of those diagnosed with dementia in East Lothian. The majority of people diagnosed are in the categories Scottish and Other British. However, a significant proportion of people responding (26%) did not have their ethnicity recorded either because it was refused, was not provided, or was not known. Only 5 people had their ethnicity recorded as either Polish, Other White Ethnic Group or Mixed/Multiple Ethnic Group.

Diagnosis and Support for People with a Learning Disability

There is an increased prevalence of dementia in those with a learning disability, particularly among people with Down Syndrome. Psychologists within the Community Learning Disability Team (CLDT) proactively complete baseline assessments for people with Down Syndrome after the age of 35 and review these annually to monitor for changes. At present there are 10 people with a Learning Disability with a diagnosis of dementia. The majority of these have Down Syndrome and are in their 50's and 60's. Only one person with a diagnosis is their 40's.

There are over 700 adults with a learning disability living in East Lothian.

There is a broad range of support available both pre and post-diagnosis from the wider Learning Disability service which takes a multi-disciplinary approach. The Learning Disability Service includes Social Work, Community Learning Disability Team and Community Resources and can provide support with:

- monitoring physical and mental health
- working with family to determine how the client is managing at home and to upskill family and next of kin to offer specific support required
- Support to assess functional ability
- Continence care
- Support with dysphasia/difficulties eating and drinking
- Dietetics and assessment of nutrition
- Mental health and memory support
- Medication reviews and prescribing

Many people with a Learning Disability already have substantial support packages in place prior to a dementia diagnosis given the life-long condition of an LD diagnosis. This is a fundamental difference to older people diagnosed with dementia. Support also tends to evolve with the person and therefore there can be less of a shift required once a dementia diagnosis is in place and more of a gradual adding on of support as the condition changes.

A further benefit of the Learning Disability service is that reviews are completed 6 monthly once a diagnosis is in place to determine how the client is managing, and family/guardian or support provider can self-refer into the service at any time should a function or behavioural change occur, or if additional support is required. As a result, support offered is person-centred and based on what the individual requires.

Substance Misuse and Dementia

Alcohol related brain damage (ARBD) is caused through excessive and prolonged use of alcohol and can result in symptoms of dementia. Although there is the potential for the damage to be partially reversed through reducing or ceasing alcohol consumption, for a portion of people with ARBD, the damage can be permanent.

There is currently a wide variation in incidence and prevalence estimates of those with alcohol-related cognitive impairment. These have been complicated by differing patterns of alcohol use as well as other associated lifestyle risk factors among alcohol abusers including head injury, other psychiatric or substance abuse co-morbidities and a higher rate of vascular risk factors. One study indicated high rates of dementia in alcohol abusers (ranging from 10% to 24%) while other prevalence studies showed high rates of alcohol abuse among people with dementia (9% to 22%).[10]

Alcohol related dementia typically has a younger age of onset than other forms of dementia and those affected are more likely to be male. Social isolation is also common among those who abuse alcohol with a high proportion of ARBD patients being unmarried or lacking the support of family or friends. Also of note is an increase in reported rates of alcohol abuse among older people and women.

East Lothian currently uses the ARBD clinic in Milestone, Edinburgh to provide support, rehabilitation and treatment to those with alcohol related brain damage. The service uses a person centred and assets based approach to identify needs and to develop a plan to support people to return home. Within East Lothian the most common age range for people to experience issues with alcohol abuse is among those aged 40-70.

Mid and East Lothian Drug and Alcohol Partnership (MELDAP) have highlighted that alcohol use amongst this age group is more likely to be attributed to other factors such as depression and social isolation. Older age groups also are more likely to be prescribed medication for other health issues and there are often contraindications when mixing these with alcohol.

Homelessness and dementia

The East Lothian Homelessness Team advise that only a very small portion of those presenting as homeless in East Lothian are over the age of 65. The context of homelessness in the county is very different from the presentation in larger cities such as Glasgow or Edinburgh. In East Lothian there are very few rough sleepers and therefore the older homeless population in East Lothian do not face

[10] Ridley et al 2013: Alcohol-related dementia: an update of the evidence

the same challenges of ill-health as a result. The homeless team also advised that they currently do not have anyone on their caseload with a diagnosis of dementia.

More commonly in East Lothian, the majority of the contact will be from people who approach the Homeless Prevention Team. Cases referred to the Homelessness Team are also commonly older people who have lived in owner occupied accommodation who are unable to be discharged home from hospital due to the current state of their property. Earlier referral by the hospital discharge team to homelessness team would assist in speeding up discharge and enable the team to make earlier contact with environmental health to undertake relevant property inspections. Improved links with hospitals and GP's will also be required when a new Housing Bill is introduced in 2023 which will include wide-reaching prevention duties in a bid to end homelessness in Scotland.

Justice Services

A prison environment can present significant challenges for people experiencing a cognitive impairment. Issues around cognition may be partly hidden by the rigid schedules frequently in place in prison that can hide some of the difficulties that people with cognitive impairment may experience. This can include undertaking activities of daily living like dressing, eating and drinking at appropriate times. It is possible that many older people in prison experiencing cognitive impairment will not get a formal diagnosis of dementia.

In line with the general population, the prison population is also ageing and there are growing numbers of people in prison with ill-health. As part of the strategy further work is needed to liaise with the Scottish Prison Service NHS to understand how appropriate levels of care are delivered within a prison setting for the ageing prison population and to better understand the particular issues for those with cognitive impairment.

Justice Services in East Lothian note an increase in men currently aged between 60 - 80 who are serving historical prison sentences, with around 50-60 people in East Lothian serving custodial sentences at any one time. However, Justice Services advise the numbers of offenders returning to the community with formal diagnosis of dementia are very low.

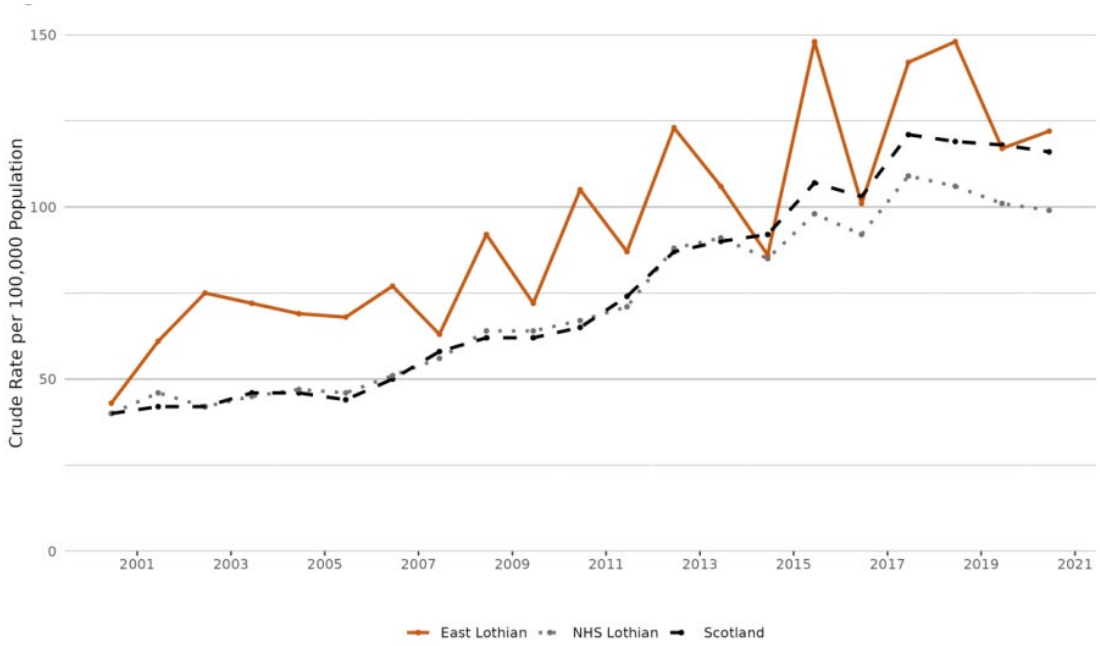
Levels of dementia in care homes

Numbers of residents with a formal diagnosis of dementia in care homes varies across East Lothian. Although residential homes do not provide nursing care, there are higher numbers of people with a diagnosis of dementia in residential homes than in our nursing homes. The percentage of people with dementia in East Lothian residential homes is around 81%, while in nursing homes, the average is around 69%.

Feedback from managers is that nursing homes tend to include residents with a wider range of frailty and other complex health conditions that require nursing care accounting for a lower number of people with a diagnosis of dementia. Nursing homes are also likely to have residents with more advanced levels of dementia. However many homes in East Lothian operate a "Home for Life" approach to maintain residents within the care home despite increasing needs. Managers in residential homes do also support residents with more advanced levels of dementia.

Deaths from Alzheimer's and Dementia in East Lothian

Figure 24. Rates of Alzheimer's Disease and other Dementia deaths in East Lothian



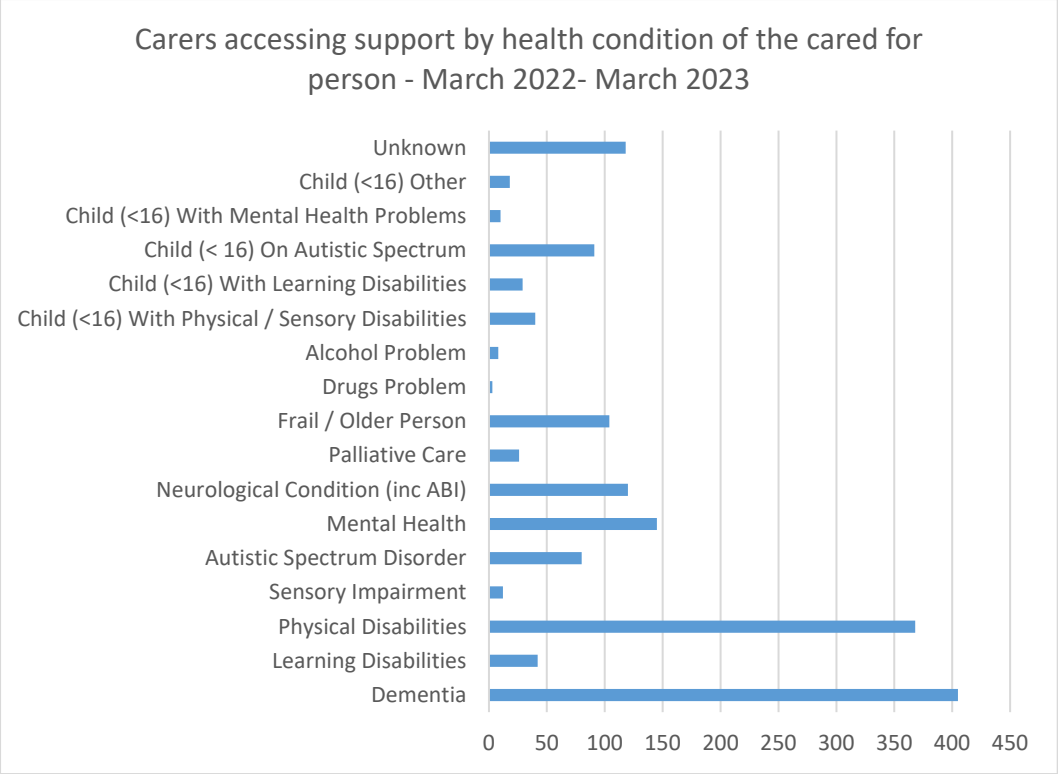
Source: National Records of Scotland [Accessed Mar 2022]

The number of Alzheimer's and other dementia deaths has increased within East Lothian (183.7% since 2000) Lothian (147.5% since 2000) and Scotland (190% since 2000). Figure 22 shows that the geographies of interest follow a similar upward trend with East Lothian showing more variance between years, likely due to a smaller population size.

East Lothian has a consistently higher rate of death due to Alzheimer's and other Dementias than Lothian and Scotland.

Carers of people with dementia

Figure 25. Carers accessing support from Carers of East Lothian by health condition



Of the total 1619 carers who accessed support from Carers of East Lothian from March 2022 – March 2023, 405 carers accessed support as a carer of someone with dementia. While it is positive that those supporting caring for someone with dementia are the largest group, we must acknowledge that this number still falls significantly below the estimated total number of people with a diagnosis of dementia (2104 in 2022). There therefore remains a significant portion of carers or someone with dementia not accessing support from a carers organisation.

Figure 26. Age range of carers of people with dementia accessing support from Carers of East Lothian

Age of Carer	Number of Carers
18 To 24	2
25 To 34	5
35 To 49	31
50 To 64	149
65 To 74	61
75 To 84	97
85 and above	28
Unknown	32

Of those who accessed support while caring for someone with dementia, the largest group of carers were aged between 50 to 64. These carers are more likely to be in employment and have family or other responsibilities. Those in employment are more likely to have to reduce their hours or give up working altogether.

We also know based on the work done through the East Lothian Carers Strategy, that it is people over the age of 65 who provide the greatest number of hours of care and who may also have health conditions of their own.

Statistics for the UK also show that women are 2.3 times more likely to provide care for someone with dementia for over 5 years, and around 60-70% of carers for people with dementia are women. It also shows that 48% of carers of someone will themselves have a longstanding disability or illness.[11]

We do not have specific data on young carers supporting people with dementia and this is something that we aim to improve on through the strategy.

Carers of someone with dementia also experience issues that are unique from other caring groups. Feedback from our local carers centre is that while carers of someone with dementia often experience similar issues as other groups, they do so at a much higher intensity given the complexity of the illness. There can be increased concerns around accessing a break from caring. Although breaks are still greatly needed, carers may find that on their return that the person with dementia's condition has worsened due to the change in their normal day-to-day routines. This then increases the stress of caring.

We are aware of the challenges of care home staff and other care at home providers in supporting people with complex dementia and have put in specialist training and advice to support these staff groups. However, for those carers caring for someone with dementia in the community, there is no such support in managing stress and distress behaviour.

Carers of those with dementia are also unique in that they frequently experience anticipatory grief, where cognitive function in the person with dementia declines in advance of their physical decline and it can feel to the carer or family like the person is slipping away. There is therefore the need to support carers in managing the emotional toll of this on their own mental health, and where peer support and counselling can be valuable in helping carers to cope.

We are also aware that more people are dying of advanced dementia rather than other diseases such as heart attack and strokes and as a result carers are now having to manage more advanced dementia in the community for longer.

Feedback from professionals is that deterioration in dementia also does not happen in a straight line but can happen very suddenly. Those within a care home setting will be able to receive increased nursing support from care home staff, but those in the community may reach crisis point quicker and may require more urgent support to support them maintain them at home. Again, the impact of this on carers must be considered. The importance of having a single point of contact at such stages would assist with this as well as the offer of longer term post diagnostic support in the form of the 8 pillar model from Alzheimer Scotland.

[11] Impact on carers - Dementia Statistics Hub

Sensory Impairment

KEY POINTS

- Prevalence of sensory impairment is more common as people age. Over 70% of those with a hearing loss are over the age of 70, and 90% of those with dementia in long term care are thought to have a hearing or vision impairment
- New research shows evidence of a link between sensory impairment and dementia, including that hearing loss is a factor in cognitive decline
- Hearing loss is one of the modifiable risk factors thought to be able to prevent or delay dementia and is estimated to account for up to 8% of dementia cases
- There is frequent under-reporting and under-treatment of sensory impairment
- Sensory impairment has a significant impact on people's health and everyday life and has been attributed to an increased risk of developing health conditions. This impact is greater on care home residents who are also likely to be living with dementia
- Hearing loss in care home residents has been shown to increase the number and severity of Neuropsychiatric symptoms which lead to poorer health outcomes.
- There are significant barriers to managing hearing and vision impairment within care homes although research shows that improvements in screening, assessments, environmental adaptations and stronger links with external professionals would improve this.

Prevalence of Sensory Impairment

Data from studies suggests that sensory impairment is more prevalent as people age:

- In Scotland there are estimated to be around 850,000 people with a hearing loss, with over 70% of those over the age of 70.[12]
- Around 1 in 10 people over the age of 65 are estimated to have a vision impairment.[13]
- Up to 90% of those with dementia in long term care are thought to have a hearing or vision impairment.[14]
- The majority of people with dual sensory loss (also known as deafblind) are older people who have developed hearing and sight loss later in life. Studies show that around 21% of adults over the age of 80 may experience dual sensory loss[15]
- Due to the projected growth in the population of those over the age of 65, those with a hearing impairment are expected to increase by 50% in the next 20 years, and those with a vision impairment are expected to double by 2031.

Sensory loss and dementia

There is also growing evidence of an association between sensory impairment and dementia. Studies now show that hearing impairment may be a risk factor for cognitive decline and brain atrophy, as well as one which may also be modifiable.[16] [17] Around 8% of cases of dementia are now attributed to hearing loss in mid-life. Hearing aid use is the largest factor protecting from cognitive decline.

[12] See Hear: Scottish Government
[13] Court et al 2014: Vision impairment is associated with physical and mental comorbidities in older adults
[14] Dawes et al 2020: Hearing and vision health for people with dementia in residential long term care
[15] Heine et al 2015: Dual sensory loss in older adults
[16] Dawes 2019: Hearing Interventions to Prevent Dementia
[17] Livingston et al 2017: Dementia Prevention, Intervention and Care

Conversely undiagnosed sensory impairment can also lead to incorrect diagnosis of more advanced cognitive difficulties. People presenting with moderate impairment who then have their hearing and vision difficulties correctly assessed and treated, may then have a lower level of impairment diagnosed.

Sensory impairment and impact on health

Sensory impairment can have a significant impact on people's health as well as their everyday life. In addition to people experiencing difficulties in their ability to communicate, to build and maintain social connections, their mobility, navigating the environment, as well as their ability to access information and learning, people with sensory loss are also shown to have an increased risk of developing other health conditions such as stroke, hypertension and heart disease as well as depression and diabetes.[18] [19]

Care home residents with sensory impairments are, in particular, at increased risk of isolation and reduced social participation which in turn can affect their mental health and quality of life. Care home residents have less control over their environment and therefore activities that were previously enjoyed such as listening to music, watching television or general socialisation and participation may be hindered.

Neuropsychiatric symptoms (NPS) such as depression, agitation, apathy and distressed behaviour are also commonly associated with those with dementia. These are often frequently associated with poorer health outcomes including institutionalisation, prolonged hospitalisation and higher morbidity and mortality. Hearing loss in care home residents with dementia has been shown to increase both the number and severity of Neuropsychiatric symptoms.[20]

Factors that hinder treatment and management of sensory impairment

It is also common for people to delay seeking help with vision or hearing loss due to a belief that it is a normal part of aging and as a result there can be delays of up to 10 years in people addressing hearing loss. In addition, studies have also identified that between 30 and 45% of adults who report hearing problems to their GP are not referred to NHS hearing services.[21]

As a result of hearing loss being underreported and untreated among older adults, only 1 in 7 people with a hearing impairment use a hearing aid for hearing loss while up to 30% of those who do own a hearing aid do not use them or use them infrequently. [22] [23]

Residents with dementia in care homes can experience additional barriers to managing hearing and vision impairment including:

- Lack of training for care home staff who are therefore not able to identify sensory loss
- Hearing aids or glasses not being used as intended
- Loss of dexterity resulting in residents being unable to effectively handle and manage their own hearing aids
- Lack of screening for impacted wax which can cause pain and present as hearing loss
- Poor links between care home and hearing and vision services resulting in infrequent optometric and audiological assessments for residents

[18] Andrusjak et al 2020: Identifying and managing hearing and vision loss in older people in care homes
[19] Court et al 2014: Vison impairment is associated with physical and mental co-morbidities in older adults
[20] Kim et al 2021: Association of hearing loss with Neuropsychiatric Symptoms in older adults with cognitive impairment
[21] NICE: Hearing loss in adults: assessment and management
[22] Kim et al 2021: Association of hearing loss with Neuropsychiatric Symptoms in older adults with cognitive impairment
[23] Dawes 2019: Hearing Interventions to Prevent Dementia

- Reliance on family members accurately reporting hearing or vision impairments for pre-admission assessments due to cognitive decline in residents. Family members frequently do not identify these as issues
- Cognitive decline impacting on performance during hearing and vision assessments

Engagement

Over the course of 2022 numerous engagement events were held as part of the work of developing the East Lothian IJB Strategic Plan and the Planning for an Ageing Population project. Events took place between April and September and in total we spoke to over 1500 people. Around 660 people attended sessions or fed into questionnaires where dementia was mentioned. Feedback was gathered from Day Centre attendees and staff, Community forums, Health and Wellbeing subgroups, locality engagement, carers, veterans and a range of Health and Social Care Partnership staff as well as from online consultation questionnaires accessible to the public.

East Lothian Health and Social Care Partnership also commissioned a separate piece of community engagement specifically for people living with dementia and their unpaid carers. Events took place between July and October 2022 using a storytelling approach. The work was led by Outside the Box in partnership with Alzheimer Scotland, Harlawhill Day Centre, The Fraser Centre, Dementia-Friendly East Lothian and RVS. In total 5 group sessions using a storytelling approach were held at different venues across east Lothian including in Dunbar, Tranent, Musselburgh and Prestonpans. Sessions were also hosted with staff, volunteers and carers. During the course of the consultation, Outside the Box spoke with 117 people.

Separate 1:1 engagement was also completed with care home managers across East Lothian to further understand the experience of care home staff in supporting people with dementia at the more advanced stages of the illness.

The Life Changes Trust also held an event in May 2018 for carers of people with dementia offering carers a chance to think about how carers can care for themselves as well as their loved ones. Information and feedback from the event offers valuable insights to help inform improvements of services from a carers perspective. 26 carers attended this event.

Feedback from all these events have been combined into 7 main themes which are categorised below. A full timetable of events are listed in Appendix B.

The Dementia Diagnosis and the First Year of Support

People with dementia and their carers told us that it can be difficult to identify themselves or their family member as having dementia as it's not always recognisable. There can be a tendency to put everything down to age-related forgetfulness which can delay visiting their GP. Early identification is key for families and people with dementia to ensure access to services and support.

It was felt that more could be done around early intervention and prevention as new research shows that promoting good health care, wellbeing and socialisation can help prevent up to 1/3 of dementia cases. People of all ages could be involved in this work to have a positive impact on future generations.

When asked about their experience around diagnosis people with dementia and their carers highlighted concerns that they were having to wait significant lengths of time to receive a diagnosis, citing difficulty in getting primary care appointments. Many family carers reported experiencing a 'gap' between receiving a diagnosis and getting further information and support.

Although people were aware that they are entitled to a 'year of support' there was little clarity around what that year of support should actually look like and a sense they were not informed as to what that entitlement meant in practice. People with dementia also cited being placed on a waiting list for support, in some cases taking them past 'the window' for receiving it as their dementia had advanced to the stage where other support was needed. Carers also told us that there was a lot of support available during the post-diagnostic period but it was difficult to navigate. A transition strategy is also needed for when the 1 year support ends.

A lack of support for carers and those living with dementia was also noted as well as a sense of frustration that practice is not getting any better, and in some cases is getting worse. Carers felt they are being forced to refuse to take loved ones home to push services into action for the support needed at home. Carers and family members also felt that they should be better informed as to what they need to consider such as equipment, prompts, personal care and power of attorney.

Concerns were voiced around the fact there is no clear single point of contact as well as pressures on the Community Mental Health Team, and suggested workers be dotted across the different localities. There is also the issue of workers changing regularly, having to get to know people from scratch, or different workers dealing with the same patient.

Reviews of the person living with dementia were always focused around their clinical state rather than their mental health. Others felt the dementia test itself was unreliable, producing a diagnosis for some and not others.

Finding Information

A common theme across all consultation events was the general lack of knowledge around where to get information about dementia, support and opportunities to take part in local activities. Carers felt that there was a lot of information out there but it remains a challenge to access this at the right time. Finding out about suitable activities or groups is a 'postcode lottery' and depends on who you speak to. Many people with dementia and their carers found information or groups by chance or through informal chats with others. Being part of one group (such as the D-café or Open Arms Carers) led to signposting and finding out useful information. People with a sensory impairment or those living alone found it even more challenging with written information not always provided in an accessible format.

Several people cited the difficulties in completing forms for benefits and reductions including the Council Tax form and Blue Badge form, particularly if these are online for those who are not 'tech

savvy'. Managing the requirements of the person with dementia can often mean carers don't have the time to complete the forms required.

A key issue that was consistently raised was that more could be done to work collaboratively across the community to effectively raise awareness of how to receive support and sign-posting. There was recognition that this involves effort and resources which can stretch the capacity of local community organisations and groups. Despite this, these community support plays a pivotal role in delivering local opportunities for people living with dementia.

Many people spoke highly of the following services:

- Alzheimer Scotland D-café which runs in three different locations and offers ongoing support and information between times.
- Carers of East Lothian offering support for carers regarding benefit and welfare advice from the Tranent Library.
- Open Arms Carers group – offering peer support across a complex landscape of what it means to be a carer for loved ones living with dementia
- The Fraser Centre – community base offering dementia friendly space, including trained staff, dementia-friendly films and hosting the D-café.
- The Volunteer Centre East Lothian – a good source of information including providing a community directory which highlights 10 different groups and organisations for those with dementia
- Dementia Friendly East Lothian – active in spreading a positive message about dementia in the community.
- Radio Saltire – good means for promoting opportunities
- RVS – offer a good library of signposting to different organisations

While people with dementia and their carers felt volunteers played an integral role in keeping these community activities going, there is a gap in volunteering as many people are unsure as to how to go about it. More could be done to promote information in different formats, without the assumption that everyone has access to a digital device. Library staff also spoke of how they would like to do more dementia training to support enquiries to their service and often receive frequent requests for information for people living with dementia.

Access and Transport

Many spoke of the challenges in accessing transport, particularly when attending medical appointments in Edinburgh. East Lothian is a large rural area dotted with small towns but with relatively poor transport links depending on where you live. While Dunbar and some other towns are well connected because of the train, buses can be irregular or not turn up. Without access to a car, attending appointments can be difficult and force people to rely on family or friends to get there. There was also a preference to use public transport to relieve the stress of driving.

RVS provides a community transport system which matches volunteers with their own cars to service users who need to attend appointments. The service is especially useful for those living in rural areas and people using the service often have a dementia diagnosis or memory loss. Issues can arise when there are no family members or friends to inform drivers about details of appointments if the person needs assistance. At times volunteers also don't have time to stay for the duration of the appointment and people with dementia using the service can get lost in hospital depending on whether there are any hospital-based volunteers available.

One person expressed concern that there was no transport to the new Musselburgh Meeting Centre for people living in rural and outlying areas.

Health and Social Care

There was a general consensus that improved communication between health and social care departments and organisations would help. Workers are allocated to cases until the person's need is met and then cases are closed until another need is raised. This led to inconsistency in terms of information not being passed on. Although there was recognition that social workers are overstretched, the current system results in people feeling like people with dementia and their carers are being "passed around".

Relationships are key to joined-up care for the person with dementia and to carer wellbeing and relationships needs time. This can mean time to build trust with a paid carer, to nurture relationships with family and friend, or enough time in appointments with professionals to be able to say what you want to say and be heard.

Many carers reported they were not being supported until they reached crisis point even though they try to raise issues as they arise and of the fight to get support in place. Earlier intervention would help people with dementia build routines that could help them self-manage for longer. Improvements in dementia training for staff are also required with people feeling that some nurses and other health professionals discounted dementia as an illness. Carers compared the system that follows cancer patients as being a preferred model which could be replicated for those with dementia where workers are employed partly by Macmillan and partly by NHS and availability of a one stop shop for people to phone.

Carers of people with dementia spoke of the importance to have permission to think about their own health and wellbeing to make quality of life more sustainable. Many carers often wait too long for mental health support. Better promotion of advocacy services is also needed as not all carers know about it, or what it offers.

There was a sense that dementia is not being dealt with holistically and there is little recognition of the various physical and sensory disabilities and emotional decline related to dementia. Emotional support should also be provided to those living with dementia and their families, particularly those in denial about their diagnosis. Peer support groups were cited as a valuable asset for this and viewed by many as a 'lifeline'

Provision of physical aids was important to the carers we spoke to although there remain significant gaps. We heard of carers having to carry out heavy lifting for self-care at home such as showering with no physical aids in place and having to wait months, in some cases opting to cover the significant cost to have changes made themselves.

Accessing respite is also very challenging with little on offer, making it difficult to attend health appointments and other work and life responsibilities. Carers report opting to pay for this themselves just to get by and arranging support can take significant planning.

Going into hospital can be traumatic for someone living with dementia. People with dementia and their carers felt that more should be done locally at East Lothian Community Hospital to avoid stressful and lengthy visits to Edinburgh acute hospitals. Local appointments for issues such as minor injuries, dental care, audiology or X-rays should be made available to avoid the stress and associated expense of attending these in Edinburgh. It was also felt that hospital staff lack awareness of dementia citing cases where staff did not feed patients as they were unable to answer, or care that was provided that lacked personal dignity.

Almost all care home managers reported that the residents coming into the homes had more complex needs, had more advanced dementia and were frailer than in the past. The vast majority of

residents in care homes now have a diagnosis of dementia. Many homes reported difficulties with staffing and recruitment with appropriate staffing levels key to providing quality support.

Almost all managers spoke very highly of the ELCHASE service which provides support, medication reviews and guidance for managing residents with stress and distress behaviour with some managers reporting they would not have been able to continue to care for some residents without this support. Some felt that medication changes could take time though.

Many managers felt that availability of training for staff was key, and although the homes had general dementia training in place, face-to-face bite size training and sensitisation training to help staff understand the experience of having dementia would make a difference in the provision of quality care. This can be difficult to access and although has been offered by ELCHASE in the past, there is not sufficient capacity in the team to do this widely.

Many homes operate a 'home for life' approach, caring for residents to the end of life and avoiding hospital admission where possible. Palliative and end of life care was reported to be good with District Nurses supporting when needed.

Feedback from managers was that accurate social work assessments at point of admission were important to ensure they could provide appropriate support for the resident and that they fit within their dependency levels. Assessments could be of a better standard.

While managers worked to ensure a range of activities are available, many community and intergenerational activities had stopped over COVID. Homes were at different stages of re-implementing these. Feedback was that continued connection to the community was important and improved resident's mood and outlook. One home in Musselburgh reported continued support from local businesses.

Community Understanding and Education

There was general agreement that a complete shift in culture and attitudes would be one of the most helpful things to support people living with dementia, including greater acceptance and understanding in shops, cafes and the wider community to enable people to be independent for longer. There are many ways people with dementia can continue to lead their lives positively following a diagnosis.

Changes in the language used to describe people with dementia both in professional and wider settings would help reduce barriers and stigma. When applying for benefits or entitlements, the language used in forms is extremely outdated such as "severely mentally impaired or incapacitated" that it puts people with dementia off applying for help. As a result some people with dementia reported preferring to hide their diagnosis than be open about it for fear of the outcome. Extra stigma and discrimination are also faced by some people with dementia and carers, including people who are lesbian, gay, bisexual and transgender.

Stigma could also be challenged by supporting more people with dementia to lead and run things. It is important to recognise that people with dementia can still work, volunteer and give back, and leading an active life can help maintain their dignity and respect. Exploring the Deepness project model would be helpful where people with dementia and unpaid carers are working together to re-write governance and guidance for Meeting Centres. Having people with dementia on key groups is also key to tapping into their lived experience.

There was also the sense that communities want to support people living with dementia and felt the strategy could help link up dementia friendly communities with appropriate resources, time and information to make this happen. Inclusive, accessible communities with good housing, good transport and infrastructure are key to supporting people to live well with dementia. Alzheimer

Scotland provides dementia awareness training in the community and it was felt this could be shared more widely with other groups and young people to support multigenerational awareness raising. Harlawhill staff have a "train the trainer" model – taking training they have received to other staff and people in the community. Training should also be provided by those with lived experience where people as "experts by experience" are at the heart of sharing knowledge. Carers also reported that quality community based services can help reduce unnecessary emergency strips to hospital and admissions.

For carers of people with dementia, awareness and understanding from friends and family of the impact of being a carer is important in supporting them in their role. Carers felt that the more supportive the general community was for all then the more the 'substantial and critical' aspects of caring as defined in the Carers Act would be curtailed.

Activities and Connections

Across all the engagement sessions, by far the greatest number of comments were in relation to community activities and connections, recognising that these are key to remaining active, engaged and healthy in older life as well as reducing social isolation.

People with dementia and their carers told us of the impact that a diagnosis had on existing relationships resulting in a change in the dynamics of family and friendships, and even the loss of some existing friendships. For wider families, where adult children lived away from home people, found that the person living closest to the relative with dementia often became the carer, at times resulting in friction within sibling relationships. Becoming a carer of someone with a diagnosis of dementia can mean experiencing loss and grief even before the loved one dies. It is a relationship fraught with guilt, anger and arguments due to the demands and exhaustion. Adequate support would at least make some of that process easier.

While there are groups and activities available locally for people living with dementia, it is often difficult to find out about these groups. Alzheimer Scotland groups which are held regularly in different locations were spoken of very highly. People with dementia told us that they would like these to be held more frequently than once a month. They also organise a regular walking group in Dunbar. Carers of people living with dementia spoke of the importance of access to meaningful activities for themselves in allowing them to take some time where worries and anxieties can be put on the back burner.

The Fraser Centre in Tranent was also cited as being exemplary with a range of dementia-specific events and activities as well as ensuring the centre is generally dementia-aware and inclusive. Many enjoyed both the dementia café hosted there as well as the less formal 'meetup' group which provides valuable peer support for carers of people living with dementia. The Fraser Centre also offers dementia friendly films, the friendship group and singing. The centre would like to start advertising and planning more activities but this requires money, staff time and resources.

Day centres were also cited as a valuable resource for people with more advanced in their dementia and mobility problems. Not only do they offer a varied programme of events and an opportunity to develop real relationships between staff and attendees, but they also act as a local resource for signposting to other services, provide much needed respite to carers, and provide advice and support when needed. We were told of the large waiting list for attendance at Harlawhill.

Many were impressed by the development of the new Meeting Centre in Musselburgh but would like to see this approach rolled out more widely and were keen on the idea of it developing into a local support hub to take some pressure off carers.

Some people with dementia reported not being comfortable joining a group and instead would prefer that there was wider acceptance in the community to enable them to be able to be safe when going for a walk or doing other activities they normally enjoyed. Greater focus on building dementia friendly inclusive communities would support this, understanding that continued conversation with local communities about what will work for them are needed as one size does not fit all.

There were also a range of suggestions and comments in relation to other community based activities including:

- The 'Library group' in Dunbar which offers a Dementia Carers' Support Group organising outings and trips as well as offering peer support. People attending reported the peer support as having a very beneficial effect.
- The intergenerational lunch club – more should be done to maximise the use of community buildings and spaces to promote intergenerational activities. Spaces need to be age-friendly. Work should be done with schools and pupil volunteers to promote this. Oral history projects are helpful in preserving memories and could be part of the school curriculum
- Availability of gardening projects as a way of keeping people healthy, engaged and aware of the seasons, time of year as well as a connection to people's previous interests. In Bloom and schools are doing some work on this. There were suggestions of working with housing to develop communal garden spaces as part of planning for new builds, including community parks.
- The Rehab Team felt that more could be done around developing general reminiscence groups. Although these are important people felt that it was key to remember that people with dementia should also be able to continue to develop both their present and future. Local Friendship groups around the county were thought to be very therapeutic for this.
- Developing more volunteering programmes for people living with dementia

Health and Wellbeing

We heard that for people living with dementia and their carers, the effects of dementia could take their toll in many ways. Losing connections, feeling isolated, losing self-confidence and feeling physically exhausted were common. On top of this came feelings of guilt, frustration and overwhelm. Peer support for carers was key in helping carers both emotionally and practically including finding out information, where to go for support and a place to offload. Many carers felt there was a huge amount of knowledge held by carers that could be shared with others in a similar situation, and peer support is a key way that carers can help share information.

Carers reported the difficulties and guilt that came in deciding to move loved ones into a care home. Peer support helps carers to manage these feelings. The pilot course on grief management, run by Carers of East Lothian, had helped carers to deal with grief – even before they lost their partner. Carers also reported the social isolation once their loved one had died and the difficulties in rebuilding their lives. Others had found counselling helpful.

All carers agreed it was difficult to find time for themselves and spoke of the lack of respite resources available with carers not getting the support they need. It can take several months to plan an appropriate respite break. We also heard that during COVID a local day centre provided a sitter service and other day centres were offering outreach services. Although RVS offers a buddy scheme the waiting list for this is long. Carers of East Lothian were also noted for their befriending service. Carers we spoke to wanted to find out more about the range of respite options available, including those for when people's dementia became more advanced.

The mental and emotional wellbeing of people living with dementia varied, mostly dictated by the stage they were at. While some people with dementia were unaware of their deterioration, others expressed frustration, anger at their diagnosis, fear and withdrawing into themselves.

APPENDIX A – Alzheimer's and Dementia Prevalence

Prevalence Rates of Dementia (%) given by the EuroCoDe and Harvey studies

Age group	EuroCoDe Males (Under 60 Harvey)	EuroCoDe Females (Under 60 Harvey)
30-34	0.0672	0.0672
35-39	0.0672	0.0672
40-44	0.0672	0.0672
45-49	0.0672	0.0672
50-54	0.0672	0.0672
55-59	0.0672	0.0672
60-64	0.2	0.9
65-69	1.8	1.4
70-74	3.2	3.8
75-79	7	7.6
80-84	14.5	16.4
85-89	20.9	28.5
90-94	29.2	44.4
95-99	32.4	48.8
100+	32.4	48.8

Further information can be found via the following link: Alzheimer Scotland

APPENDIX B – Timetable of Consultation and Engagement Events

Engagement events for the IJB Strategic Plan and Planning for an Ageing Population consultation:

- Health, Social Care, Housing and Place Older People Workshop (19 April 2022 – 11 people)
- Health, Social Care, Housing and Place Dementia Workshop (20 April 2022 – 10 people)
- IJB Strategic Plan questionnaire – 58 people)
- Veterans Lived Experience (5 May 2022 – circa 60 people)
- Health and Social Care, Housing and Place Making – carried out by North Berwick Community Council – self-administered engagement, based on our engagement pack (13- 15 May 2022 – circa 50 people)
- ELHSCP Business Support and Business Admin Teams (16 people)
- Scottish Government Older People's Strategy Engagement (30 May 2022 – 11 people)
- Planning and Performance Team IJB Strategic Plan Workshop (31 May 2022 – 8 people)
- Adult Wellbeing, Care and Home and Mental Health Staff IJB Strategic Plan Workshop (1 June 2022 – 32 people)
- Re-imagining Health and Social Care Questionnaire (185 online respondents)
- North Berwick Day Centre Engagements (7 and 27 July 2022) (51 participants)
- Lunch with the Bunch (14 July 2022 – 10 participants)
- Harlawhill Day Centre Engagement (19 July 2022) (14 participants)
- Dunbar Day Centre Engagement (20 July 2022) (14 participants)
- John Bellany Day Centre Engagement (21 July 2022) (16 participants)
- Rural Communities Engagement (4 August 2022) – Teams (23 participants)
- Eastern Communities Engagement (11 August 2022) – Teams (27 participants)
- Western Communities Engagement (18 August 2022) – Teams (29 participants)
- Carers Engagement (25 August 2022) – Teams (7 participants)
- Providers Engagement (29 August 2022) – Teams (11 participants)
- Dunbar Health and Wellbeing Sub Group (22 August 2022) (10 participants)
- Musselburgh Engagement (5 September 2022) (5 participants)
- North Berwick Engagement (6 September 2022) (13 participants)

Engagement events hosted by Outside the Box

Total number of people engaged with: 117
Total number of people living with dementia: 50
Total number of unpaid family carers: 40
Total number of staff and volunteers: 17 and 10
Total number of group sessions: 5

- Storytelling Session 1: Dunbar Townhouse (Alzheimer Scotland café) with c. 8 couples
- Storytelling Session 2: Fraser Centre, Tranent (Alzheimer Scotland café) – c. 6 couples
- Storytelling Session 3: (venue?) Musselburgh (Alzheimer Scotland café) – 5 people with dementia, 3 carers, 3 support workers
- Storytelling Session 4: Harlawhill Day Centre, Tranent – around 5 staff plus 4 volunteers (of whom 2 were previous family carers) + c. 12 day centre attendees (people with dementia) - some of these people from homes/sheltered housing, others from family home
- Open Arms Carers – Haddington - c. 10 people, all family carers/previous family carers, daughters, wives of people living with dementia (some widowed now)

- RVS/community transport staff: consulted with c. 4 members of staff around transport service
- Dementia-Friendly East Lothian: 1:1 chat
- Other 1:1 discussions: volunteer and former carer from Harlawhill, Manager and former family carer from Harlawhill

Engagement with East Lothian Care Home Managers

- Florabank Residential Home – 23/08/2022
- Carberry Residential Home – 13/09/2022
- Tyneholm Stables Nursing Home – 21/09/2022
- St Anne's Residential Home – 28/09/2022
- Astley House Nursing Home – 04/10/2022
- Fidra Nursing Home – 12/10/2022
- Tranent Nursing Home – 19/10/2022
- Lammermuir Nursing Home – 25/10/2022
- Crookston Residential Home – 02/11/2022
- The Abbey Residential Home – 08/11/2022
- Muirfield Nursing Home – 22/11/2022
- Harbour House Nursing Home – 30/11/2022
- Drummohr Nursing Home – 02/12/2022
- Belhaven Nursing Home – 31/01/2023
- Haddington Care Home – 08/02/2023

REPORT TO: East Lothian Integration Joint Board

MEETING DATE: 26 October 2023

BY: Chief Officer

6

SUBJECT: Review of East Lothian IJB Directions

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1 PURPOSE

1.1 The purpose of this report is to present recommendations regarding updates to the current IJB directions and the introduction of additional Core Directions to the IJB for consideration.

2 RECOMMENDATIONS

The IJB is asked to:

2.1 Approve the recommended updates to the current set of East Lothian IJB directions contained at appendix 1.

2.2 Agree the introduction of four additional Core Directions (appendix 2) to provide broad coverage of all functions delegated to East Lothian IJB.

2.3 Agree that the IJB continue to give active consideration to the introduction of additional directions as and when required, and that these be developed in line with the IJB Directions Policy.

3 BACKGROUND

3.1 A report to the May meeting of the East Lothian IJB Strategic Planning Group (SPG) recommended that the 2022/23 IJB Directions be reviewed in line with the IJB Directions Policy (agreed at a meeting of the IJB in October 2022). The report also recommended that further work be carried out on the development of a number of Core Directions in response to the requirement that directions cover all delegated functions, including delivery of hosted and set-aside services.

3.2 Subsequent to this, discussion took place with Change Board Chairs / General Managers regarding existing directions. This helped to identify updates needed to individual directions to reflect changing circumstances, as well as highlighting directions that could be retired, either because they had been completed, or due to them no longer being relevant / required. Recommendations in relation to an updated set of direction based on these discussions can be found at appendix 1.

3.3 Once IJB approval has been secured, details of budgets, performance measures, timescales, and oversight arrangements will be added for each direction using the East Lothian IJB Directions Template, reflecting the requirements of the IJB Directions Policy (template included at appendix 3).

3.4 Further discussion is still required in relation to the directions linked to the remit of the Shifting the Balance of Care (STBC) Change Board. It is anticipated that the STBC Change Board will review these over the coming months, with recommendations regarding updated directions coming to a subsequent IJB meeting.

3.5 Development has also taken place in relation to the proposed Core Directions, including the addition of budget information and other details. The four recommended Core Directions are included at appendix 2 and cover all delegated functions, including those delivered via set-aside and hosted arrangements as follows:

- Direction to NHS Lothian regarding the delivery primary and community health services.
- Direction to NHS Lothian regarding the delivery of hosted services.
- Direction to NHS Lothian regarding the delivery of set-aside services.
- Direction to East Lothian Council regarding the delivery of social work and social care services.

3.6 Going forward, and in line with the agreed policy / approach to direction setting, the IJB should continue to consider the introduction of additional directions as and when needed. Any additional directions should be introduced following a report to the IJB. The issuing of directions should be proportionate and should follow the Directions Policy in terms of including financial information and details of timescales, performance measures, etc. Examples of when additional directions may be required include:

- Where significant changes to service delivery / approach are required – for example, as the result of transformation / provisioning programmes.
- In relation to additional funding being made available (e.g., Scottish Government funding), changes to budgets, or developments regarding the use of budgets.

- To reflect the introduction of new (or updated) strategies or plans where specific action is required by delivery partners.

4 ENGAGEMENT

4.1 Engagement with Change Boards / General Managers has taken place, and will continue to take place, in relation to reviewing current directions.

5 POLICY IMPLICATIONS

5.1 The recommendations included in this report reflect the East Lothian Directions Policy. The Directions Policy was agreed by East Lothian IJB in October 2022, outlining an updated approach to issuing and managing directions in line with the statutory guidance issued by the Scottish Government in 2020.

6 INTEGRATED IMPACT ASSESSMENT

6.1 The subject of this report does not affect the wellbeing of the community or have a significant impact on equality, the environment or economy.

7 DIRECTIONS

7.1 This report relates to a review of current East Lothian IJB directions, and the introduction of new directions.

8 RESOURCE IMPLICATIONS

8.1 This paper has no specific resource implications; however, the identification of resource implications forms part of setting individual IJB directions.

9 BACKGROUND PAPERS

East Lothian IJB Directions Policy

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DATE	17th October 2023

Appendix 1 – Review of East Lothian IJB 2022-23 Directions – Recommendations

Review of East Lothian IJB 2022-23 Directions – Recommendations

Recommendation	Details	Number of directions applies to
Retire	Retiral of direction because completed / no longer necessary / superseded by Core Direction	X 10
Retain / Review	Direction to be retained in current form until reviewed by relevant Change Board	X 9
Update	Direction to be updated to reflect progress and / or new developments	X 7

Direction to NHS Lothian on Delegated Community Health Services				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D01h	East Lothian Community Hospital	NHS Lothian to work with East Lothian Health and Social Care Partnership to continue to support the development of secondary care services to meet the needs of the local community. This should include further expansion in the range of services offered at East Lothian Community Hospital, compatible with identified local need. (Revised February 2022)	Shifting the Balance of Care Change Board	**Retain / Review** Direction to be retained and reviewed by the STBC Change Board, with recommendations regarding an updated version using the directions template to be made to a future meeting of the IJB.

Directions to East Lothian Council on Delegated Adult Social Care Services				
No	**Title**	**Direction**	**Oversight**	**Recommendation**

D02f	Health and Housing and Social Care Group	East Lothian Council to better meet people's housing and social care needs through facilitation of the housing and health and social care planning interface group. The group will deliver the key actions and priorities from the 2019-22 Strategic Plan's Housing Contribution Statement, needs assessment, and reprovision plans. (Revised 2019-20)	Adults with Complex Needs Change Board	**Retire** This direction has been completed. A strategic working group for housing, health, and social care has now been established.
D02j	Transitions for Young People into Adult Services	East Lothian Council to support joint working with East Lothian Health and Social Care Partnership and other relevant partners to improve outcomes for young people with additional support needs transitioning into Adult Health and Social Care services, including establishment of robust planning, policy, and protocol. East Lothian Council to ensure ELHSCP has the opportunity to contribute to any relevant needs assessment or review of services for young people with complex needs transitioning into adult services. (New direction 2020-21)	Adults with Complex Needs Change Board	**Retire** This direction has been completed. The development of an East Lothian Transitions framework has formalised existing collaborative approaches and further defined partner responsibilities, and milestones / timescales.
D02k	Mental Health Officer	East Lothian Council to ensure delivery of a rights-based approach for patients subject to the Mental Health Act 2003 through timely access to a Mental Health Officer to help safeguard patients' rights and fulfil statutory duties, including assessment, providing information and advising on individual's rights and choices. (New direction 2020-21)	Adults with Complex Needs Change Board	**Retire** The Core Direction relating to delivery of ELC services supersedes this direction and includes the specific requirement that services are delivered in line with statutory duties.

Directions to NHS Lothian on Hosted Services				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D04b	Phase 2 Royal Edinburgh	NHS Lothian to improve in-patient experience for East Lothian residents and ensure East Lothian HSCP has appropriate influence in development, decision-making and approval of a business case for Phase 2 of the Royal Edinburgh Hospital Campus. The redevelopment should be based on the East Lothian bed numbers agreed by the IJB in April 2018. NHS Lothian to bring the business case to the IJB for agreement on bed numbers and financial model. (Revised in 2019-20)	Mental Health and Substance Use Change Board	**Update** Direction to be updated to reflect progress and to instruct further activity. Wording as follows: 'NHS Lothian is directed to support collaborative work across services to develop new models and pathways for community based mental health provision, specifically with regards to mental health rehabilitation and low secure mental health provision in community settings. This should reflect the outcomes of the bed based review and the continuation of activity aimed at bringing East Lothian's mental health acute bed use within the allocated bed capacity.'

Directions to NHS Lothian on Primary Care				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D10b	Cluster Work	NHS Lothian to allocate to East Lothian Health and Social Care Partnership its proportionate share of all funds allocated for the development and support of GP Quality Clusters in order to support further development of Quality Improvement	Primary Care Change Board	**Retire** This direction is no longer required as arrangements and appropriate support for Quality Improvement activities are in place and work ongoing.

		activities, the development of the Cluster Quality Improvement Plan (CQIP) and to meet the Cluster National Guidance. In addition, NHS Lothian to allocate a proportionate share of Quality Improvement (QI) professional support from its QI team to East Lothian GP Quality Clusters and provide access for the Primary Care Team to data support from Lothian Analytical Services (LAS) to support this programme and others as required. (Revised February 2022)		
D10d	Primary Care Improvement Plan	NHS Lothian to implement the Primary Care Improvement Plan (PCIP) for East Lothian covering all delivery arrangements for all aspects of the GMS Contract. NHS Lothian to provide ongoing support for the development of the East Lothian PCIP through Primary Care Contractor Organisation (PCCO) and other NHS Lothian Board support and development functions. (Revised February 2022)	Primary Care Change Board	**Retire** This direction is superseded by the new Core Direction relating to NHSL delivery of core primary and community health services. Work has begun on a Primary Care Development Plan that will outline the strategic direction for the development of primary care services in East Lothian. The Core Direction will be updated once the Primary Care Development Plan has been agreed by the IJB (spring 2024).
D10j	Primary Care Premises and Infrastructure	NHS Lothian and East Lothian Council to ensure sustainable premises and infrastructure, including timely implementation of eHealth solutions, for Primary Care to support future delivery of the Primary Care Improvement Plan, COVID-19 resilience, and remote access pathways. Support to premises and infrastructure to extend to future proposed developments and joint projects to support population growth in East Lothian.	Primary Care Change Board	**Update** Direction to be updated to cover all primary care services and to include premises, digital infrastructure and travel and transport. Working as follows: 'NHS Lothian and East Lothian Council to support planning, development, and investment in appropriate infrastructure to

		East Lothian Council to ensure that its Planning / Development teams consult the HSCP on all housing and care home developments at an early stage to allow the implications of any proposed / amended developments on primary care and community services to be assessed and reflected in the HSCP Primary Care Premises Strategy. (Revised February 2022)		ensure the sustainable delivery of community and primary care health services to meet the needs of the current and projected East Lothian population. This direction includes premises, digital infrastructure, and travel and transport provision.'

Directions to NHS Lothian and ELC on Reducing Use of Acute Services and Increasing Community Provision				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D11a	Emergency Admissions	NHS Lothian and its acute services to work with officers of the East Lothian Health and Social Care Partnership to continue to review and develop the provision of emergency assessment services in Lothian. NHS Lothian to continue to support redesign work currently underway which is contributing to a reduction in hospital attendances from East Lothian. (Revised February 2022)	Shifting the Balance of Care Change Board	**Retain / Review** Direction to be retained and reviewed by the STBC Change Board, with recommendations regarding an updated version using the directions template to be made to a future meeting of the IJB.

D11b	Occupied Bed Days / Delayed Discharge	NHS Lothian and East Lothian Council to work collaboratively to reduce the length of stay for all patients admitted following unscheduled admission. This is to be achieved by a reduction in delayed discharges, avoidable admissions, and inappropriately long stays in acute hospital and through the development of locally available community services and facilities, including the provision of alternatives to inpatient care. (Revised February 2022)	Shifting the Balance of Care Change Board	**Retain / Review** Direction to be retained and reviewed by the STBC Change Board, with recommendations regarding an updated version using the directions template to be made to a future meeting of the IJB.
D11d	Palliative Care	NHS Lothian to work with the Managed Clinical Network (MCN) for Palliative Care, hospital, community and third sector palliative care services to provide specialist assessment of patients in their own homes, care homes or community hospitals to maximise the delivery of patient-centred end of life care at home or in a homely setting. (Continuing direction)	Shifting the Balance of Care Change Board	**Retain / Review** Direction to be retained and reviewed by the STBC Change Board, with recommendations regarding an updated version using the directions template to be made to a future meeting of the IJB.
D11e	AHP Resource	NHS Lothian to provide information on the numbers of Allied Health Professionals (AHPs) and associated resources in acute	Shifting the	**Retain / Review**

		settings and to work with East Lothian Health and Social Care Partnership (ELHSCP) to create supportive arrangements, whereby acute staff could provide services within the community to support discharge of East Lothian residents. In tandem, ELHSCP to explore ways to in-reach to acute hospitals providing resources for assessment to improve patient flow. (Revised 2022)	Balance of Care Change Board	Direction to be retained and reviewed by the STBC Change Board, with recommendations regarding an updated version using the directions template to be made to a future meeting of the IJB.

Directions to NHS Lothian and East Lothian Council on Shifting the Balance of Care for Care Groups				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D12a	Hospital to Home and Home Care Services Review	NHS Lothian and East Lothian Council to simplify and speed up the process for assessing individual client's need for care at home and subsequently delivering services to meet assessed needs. As part of this, both organisations are required to support the ongoing development of the ICAAT (Integrated Care Assessment and Allocation Team) process and associated work. (Revised February 2022)	Shifting the Balance of Care Change Board	**Retain / Review** Direction to be retained and reviewed by the STBC Change Board, with recommendations regarding an updated version using the directions template to be made to a future meeting of the IJB.
D12l	Transforming Care for Older People	NHS Lothian and East Lothian Council to transform the service delivery to older people for the provision of Community Hospitals, Care Homes, and the development of intermediate care services, involving full engagement and consultation with appropriate parties. This should take into account demographic factors, current use of services, the impacts of COVID-19, funding pressures, service remobilisation and redesign. It must also take note	East Lothian Community Hospitals and Care Homes Provision Project Board	**Retain / Review** This direction will be reviewed and updated once the Planning Older People's Service Project concludes and the IJB has reached a decision regarding future service development / delivery.

		of the emerging outputs from the Independent Review of Adult Social Care and development of a National Care Service. (Revised February 2022)		
D12j	Extra Care Housing Implementation	East Lothian Council Housing and Officers of East Lothian Health & Social Care Partnership to: • Maximise independent living • Provide specific interventions according to the needs of the service user • Provide a clear care pathway which connects services • Contribute to preventing unnecessary hospital admission through implementation of recommendations from the extra care housing review (New direction 2019-20)	Strategic Planning Group	**Retire** This direction is no longer relevant in terms of the HSCP approach to meeting older people's housing needs.

Directions to NHS Lothian and East Lothian Council on Support to Carers				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D14a	Carer's Strategy Implementation	NHS Lothian and East Lothian Council to review existing outcomes in the East Lothian Carers Strategy to ensure carers in East Lothian continue to be identified, informed, and supported to maintain their own health and wellbeing, taking into account the short and medium term impact of COVID on carers and prioritising actions to mitigate this.	Carers Change Board	**Update** Direction to be updated to reflect agreement of revised East Lothian Carers Strategy. Wording as follows: 'NHS Lothian and East Lothian Council to support the delivery of the outcomes contained in the East Lothian Carers Strategy (2023-26) and the associated Action Plan in order to meet the needs of both adult and young carers.'

Directions to East Lothian Council and NHS Lothian on Drug and Alcohol Services and Mental Health				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D15c	Mental Health Triage	NHS Lothian and ELC to work together to further develop Mental Health services across primary and secondary care. This will include services working together to refine and streamline access to services taking in to account the unscheduled care redesign. We will establish a clear interface between primary, secondary care and the third sector to ensure individuals receive the right level of support at the right time. (Revised September 2020)	Mental Health and Substance Use Change Board	**Update** Direction to be updated to reflect progress made following the review of access to mental health services in East Lothian and to instruct further activity. Wording as follows: 'NHS Lothian and East Lothian Council to work together to further develop Mental Health services across primary and secondary care. This should include the continuation of collaborative work to refine and streamline access to services and establish a clear interface between primary, secondary care and the third sector, and ongoing inclusion and development of the clinical decision making role within the CWIC Mental Health service and rollout of the Distress Brief Intervention service. Activity should also include specific collaboration to improve access to services and the development of pathways for people with co-occurring drug / alcohol and mental health difficulties to enable them to receive mental health support and drug / alcohol support concurrently. Development should be in line with requirements outlined in Medication Assisted Treatment (MAT) Standard 9.'
D15i	Mental Health Housing	East Lothian Council to work with East Lothian Health and Social Care Partnership to develop a strategic approach to housing for individuals with a mental illness through the	Mental Health and	**Retire**

	Strategic Approach	development of a Joint Strategic Needs Assessment to inform the next Local Housing Strategy 2023-28. (Revised February 2022)	Substance Use Change Board	Direction to be retired as superseded by the updated version of direction D18h (below) which covers a range of particular housing needs, including needs related to mental health.
D15k	Centralised Alcohol Services Review	East Lothian Council and NHS Lothian to improve access to alcohol services through supporting East Lothian Health and Social Care Partnership to review and further develop local delivery of alcohol services. (Revised February 2022)	Mental Health and Substance Use Change Board	**Update** Direction to be updated to combine D15k and D15m. Wording as follows: 'NHS Lothian and East Lothian Council are directed to work collaboratively with Midlothian and East Lothian Drug and Alcohol Partnership (MELDAP) and third sector providers and to further develop and improve the multi-agency approach in relation to access to alcohol and drug support services. Development should be in accordance with statutory / regulatory requirements where applicable and aiming to meet both local and national targets, including MAT (Medication Assisted Treatment) Standards.'
D15l	Psychological Services Delegation	NHS Lothian to improve access to psychological services within East Lothian by reducing waiting times for East Lothian residents in line with the trajectories for psychological therapies as specified by the Scottish Government. (Revised September 2020)	Mental Health and Substance Use Change Board	**Retire** This Core Direction relating NHS hosted services cover this direction and includes a specific requirement that service delivery is in line with local and national targets (in this case, Scottish Government targets).
D15m	Substance Misuse Services	East Lothian Council and NHS Lothian to tackle inequalities through the delivery of the Midlothian and East Lothian Drug and Alcohol Partnership (MELDAP) Plan, and to improve access to Substance Misuse Services for people in East	Mental Health and Substance	**Update** Direction to be updated to combine D15k and D15m. Wording as follows:

		Lothian. This includes supporting East Lothian HSCP to ensure robust management and oversight of the MELDAP Plan. (Revised September 2020)	Use Change Board	'NHS Lothian and East Lothian Council are directed to work collaboratively with Midlothian and East Lothian Drug and Alcohol Partnership (MELDAP) and third sector providers and to further develop and improve the multi-agency approach in relation to access to alcohol and drug support services. Development should be in accordance with statutory / regulatory requirements where applicable and aiming to meet both local and national targets, including MAT (Medication Assisted Treatment) Standards.'

Directions to East Lothian Council and NHS Lothian on Community Justice & Equalities				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D16a	Community Justice Partnership	ELHSCP to work with Community Justice Partnership to: • Improve understanding of community justice • Ensure Strategic planning and partnership working • Offer equitable access to services • Develop Evidence based interventions (Revised in 2019-20)	Planning & Performance Team	**Retire** This direction is no longer required as the Community Justice Partnership is now well established with partners, including NHS Lothian and East Lothian Council, collaborating on the delivery of the Community Justice Local Outcome Improvement Plan.
D18c	Fairer Scotland Action Plan	East Lothian Council to help tackle poverty, reduce inequality and to contribute to building a fairer and more inclusive Scotland through production and delivery of a local implementation plan for the Fairer Scotland Action Plan. This work must provide greater opportunities to participate in local consultations and ongoing monitoring of hate crimes against people with disabilities.	Planning & Performance Team	**Retire** This direction is no longer required. ELHSCP services continue to contribute to work led by East Lothian Council in relation to tackling poverty through the Poverty Working Group and delivery of actions within the East Lothian Poverty Plan.

Directions to NHS Lothian and East Lothian Council on Adults with Complex Needs				
No	**Title**	**Direction**	**Oversight**	**Recommendation**
D18h	Housing for Particular Needs	East Lothian Council to maximise independent living for people with particular needs which includes Learning Disability and people with Physical Disability and/or Sensory Impairment. East Lothian Council to support the development and delivery of different housing models for people with support needs through the development and implementation of its Local Housing Strategy.	Adults with Complex Needs Change Board	**Update** Direction to be updated to include coverage of particular housing needs related to mental health (superseding direction D15i). Wording as follows: 'East Lothian Council is directed to support the development and delivery of different housing models for people with support needs through the development and implementation of its Local Housing Strategy. This should be carried out with the objective of maximising independent living for people with particular needs including those related to Learning Disability, Physical Disability, Sensory Impairment, and Mental Health conditions. As part of this direction, East Lothian Council should deliver up to 60 units of core & cluster housing between 2024-29 for the above client groups, dependant on IJB funding and the delivery of the Affordable Housing Supply Programme (AHSP).' A further update to this direction should be considered once the East Lothian Local Housing Strategy and Housing Contribution Statement are agreed.
D18i	Community Transformation	East Lothian Council and NHS Lothian to ensure that supports and services provided are in line with the remobilisation plan, take into account the views of people	Adults with Complex Needs	**Retain / Review**

	Programme – Under 65s	with lived experience, and are based on a human rights and person centred approach.	Change Board	Consideration should be given as to whether an updated direction is required to support the ongoing implementation of the Transformation Programme, or whether service changes are now sufficiently embedded and established (in which case, delivery is covered by the Core Direction to ELC).
D18j	Community Transformation – Over 65s	East Lothian Council to develop its approach to day services based on providing high quality, community-based services, accessible to residents over 65 across the county. Where appropriate, the new and innovative approaches necessitated by COVID-19 should be continued and further developed. In addition, day service provision should be available in order to fulfil the responsibility to provide breaks from caring.	Adults with Complex Needs Change Board	**Retain / Review** See direction D18i above.

Appendix 2 – East Lothian Integration Joint Board Directions – Proposed Core Directions

Title of direction and reference number	**NHS Lothian delivery of core primary and community health services – ref DC.1 (NEW)**
Date direction issued by IJB	TBC
Direction to	NHS Lothian
Does this direction supersede, amend, or cancel a previous direction? If yes, include reference number	Supersedes a number of Directions (reference numbers to be added)
Services / functions covered	This Direction covers primary and community health services delegated to East Lothian IJB as required by the Public Bodies (Joint Working) (Scotland) Act 2014 and outlined in East Lothian IJB's Integration Scheme. • Community Hospitals (East Lothian Community Hospital, Edington, Belhaven) • Community Nursing (including children's community health services, district nursing, health visiting and school nurses) • Community mental health services • Community learning disability services • Substance misuse services • Allied Health Professionals • General Medical Services • General Dental Services • General Ophthalmic Services • Community Pharmacy • Palliative Care provided outwith a hospital

	• Community continence service • Kidney dialysis services outwith a hospital • Community Complex Care
Full text of direction	NHS Lothian is directed to continue the provision of the services listed within current budgets detailed below and in accordance with any statutory / regulatory obligations where applicable and aiming to meet both national and local targets. Service development and delivery should be in line with East Lothian IJB's strategic objectives and strategic delivery priorities as laid out in its Strategic Plan for 2022-2025. In relation to Primary Care services (General Medical Services, General Dental Services, General Ophthalmic Services and Community Pharmacy), NHS Lothian is directed to support delivery of services in accordance with the priorities outlined in East Lothian Primary Care Improvement Plan (PCIP). The PCIP will be replaced by a new Primary Care Development Plan in spring 2024 which will provide further detail on the priorities for the development of primary care in East Lothian (this direction will be updated once the new Plan has been agreed). Services in the list above may be the subject of additional Directions where required in response to changing circumstances, including in response to service reviews, transformation programmes, strategic developments, or financial / budget changes.
Link to relevant IJB report	East Lothian IJB Strategic Plan 2022-25 Primary Care Improvement Plan (PCIP) – 2019 Update

<table>
<tr><td>Budget allocation from IJB to carry out direction</td><td>
<table>
<tr><th>Core Health Budget 2023/24</th><th>£,000</th></tr>
<tr><td>Community Equipment</td><td>656</td></tr>
<tr><td>Community Hospitals</td><td>13,313</td></tr>
<tr><td>District Nursing</td><td>3,335</td></tr>
<tr><td>GMS</td><td>18,862</td></tr>
<tr><td>Health Visiting</td><td>2,220</td></tr>
<tr><td>Learning Disabilities</td><td>590</td></tr>
<tr><td>Mental Health</td><td>6,533</td></tr>
<tr><td>Prescribing</td><td>21,420</td></tr>
<tr><td>Resource Transfer</td><td>4,969</td></tr>
<tr><td>Therapy Services</td><td>7,523</td></tr>
<tr><td>Substance Misuse</td><td>245</td></tr>
<tr><td>Primary Care Services</td><td>5,082</td></tr>
<tr><td></td><td>85,467</td></tr>
</table>
</td></tr>
<tr><td>Alignment with IJB Strategic Objectives / Delivery Priorities</td><td>This Direction relates to the following strategic objectives outlined in the IJB Strategic Plan:

1. Develop services that are sustainable and proportionate to need
2. Deliver new models of community provision, working collaboratively with communities
3. Focus on prevention and early intervention
4. Enable people to have more choice and control and provide care closer to home as appropriate
5. Further develop / embed integrated approaches and services
6. Keep people safe from harm
7. Address Health inequalities</td></tr>
</table>

	Within each of the Strategic Objectives there are a number of Strategic Delivery Priorities related to the services identified in this direction, with further details regarding these contained in the ELHSCP Annual Delivery Plan.
Compliance and performance monitoring	Performance in relation to delivering this Direction will be monitored by review of the following: • National and local performance targets • Milestones and performance measures outlined in East Lothian IJB's Annual Delivery Plan and reflected in the East Lothian HSCP Performance Framework • Milestones and performance measures in the East Lothian Primary Care Improvement Plan NHS Lothian is required to provide performance information to the IJB in relation to performance against local and national targets and with respect to performance indicators contained in the ELHSCP Performance Framework. NHS Lothian is also required to provide financial analysis, budgetary control, and monitoring reports as and when requested by the IJB. These reports should set out the financial position and outturn forecast against budget allocations by the IJB to NHS Lothian with respect to delivering integrated health services.

Title of direction and reference number	**NHS delivery of hosted services – ref DC.2 (NEW)**
Date direction issued by IJB	TBC
Direction to	NHS Lothian
Does this direction supersede, amend, or cancel a previous direction? If yes, include reference number	Supersedes a number of Directions (reference numbers to be added)
Services / functions covered	This Direction covers services provided as part of a single Lothian-wide service, referred to as 'hosted services' and managed on a pan-Lothian level by a Chief Officer of one of the Lothian IJBs in their role as a Joint Director of NHS Lothian. These services are outlined in East Lothian IJB's Integration Scheme and are as follows: • Public Dental Service • Clinical Psychology • Podiatry • Mental Health (inpatient and psychiatric rehabilitation) • Sexual & Reproductive Health • Dietetics • Art Therapy • Adults with Complex and Exceptional Needs • SMART Centre • Hospices and Palliative Care • Pulmonary Rehabilitation • Community Equipment Loan Service • Continence

<table>
<tr><td></td><td>

- Rehabilitation Medicine

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<tr><td>Full text of direction</td><td>NHS Lothian is directed to continue the provision of the services listed within current budgets detailed below and in accordance with any statutory / regulatory obligations where applicable and aiming to meet both national and local targets.

Service development and delivery should be in line with East Lothian IJB's strategic objectives and strategic delivery priorities as laid out in its Strategic Plan for 2022-2025.

Services in the list above may be the subject of additional Directions where required in response to changing circumstances, including in response to service reviews, transformation programmes, strategic developments, or financial / budget changes.</td></tr>
<tr><td>Link to relevant IJB report</td><td>East Lothian IJB Strategic Plan 2022-25</td></tr>
<tr><td>Budget allocation from IJB to carry out direction</td><td>

Hosted Budget 2023/24	£,000
Hospices & Palliative Care	550
Learning Disabilities	1,589
LUCS	1,401
Mental Health	2,534
Oral Health Services	762
Psychology Services	874
Rehabilitation Medicine	1,106

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Sexual Health	865
Substance Misuse	341
Therapy Services	1,503
UNPAC	789
Other	1,350
Total	**13,663**

Alignment with IJB Strategic Objectives / Delivery Priorities	This Direction relates to the following strategic objectives outlined in the IJB Strategic Plan: 1. Develop services that are sustainable and proportionate to need 2. Deliver new models of community provision, working collaboratively with communities 3. Focus on prevention and early intervention 4. Enable people to have more choice and control and provide care closer to home as appropriate 5. Further develop / embed integrated approaches and services 6. Keep people safe from harm 7. Address Health inequalities Within each of the Strategic Objectives there are a number of Strategic Delivery Priorities related to the services identified in this direction, with further details regarding these contained in the ELHSCP Annual Delivery Plan.
Compliance and performance monitoring	Performance will be monitored by review of the following: • National and local performance targets • Milestones and performance measures outlined in East Lothian IJB's Annual Delivery Plan and reflected in the East Lothian HSCP Performance Framework

	NHS Lothian is required to provide performance information to the IJB in relation to performance against local and national targets and with respect to performance indicators contained in the ELHSCP Performance Framework. NHS Lothian is also required to provide financial analysis, budgetary control, and monitoring reports as and when requested by the IJB. These reports should set out the financial position and outturn forecast against budget allocations by the IJB to NHS Lothian with respect to delivering integrated health services.

Title of direction and reference number	**NHS delivery of set-aside services – ref DC.3 (NEW)**
Date direction issued by IJB	TBC
Direction to	NHS Lothian
Does this direction supersede, amend, or cancel a previous direction? If yes, include reference number	Supersedes a number of Directions (reference numbers to be added)
Services / functions covered	This Direction covers services provided under set-aside arrangements whereby NHS Lothian delivers delegated functions based in large hospitals on behalf of IJBs. These services include: • Accident and Emergency and Combined Assessment • General Medicine • Geriatric Medicine • Rehabilitation Medicine • Respiratory Medicine • Hospital based Palliative Care
Full text of direction	NHS Lothian is directed to continue the provision of the services listed within current budgets detailed below and in accordance with any statutory / regulatory obligations where applicable and aiming to meet both national and local targets.

<table>
<tr><td></td><td>Services in the list above may be the subject of additional Directions where required in response to changing circumstances, including in response to service reviews, transformation programmes, strategic developments, or financial / budget changes.</td></tr>
<tr><td>Link to relevant IJB report</td><td>East Lothian IJB Strategic Plan 2022-25</td></tr>
<tr><td>Budget allocation from IJB to carry out direction</td><td>
<table>
<tr><th>Set Aside Budget 2023/24</th><th>£,000</th></tr>
<tr><td>ED & Minor Injuries</td><td>2,481</td></tr>
<tr><td>Cardiology</td><td>860</td></tr>
<tr><td>Gastroenterology</td><td>1,342</td></tr>
<tr><td>General Medicine</td><td>6,343</td></tr>
<tr><td>Geriatric Medicine</td><td>3,330</td></tr>
<tr><td>Infectious Disease</td><td>1,512</td></tr>
<tr><td>Junior Medical</td><td>516</td></tr>
<tr><td>Rehabilitation Medicine</td><td>366</td></tr>
<tr><td>Respiratory Medicine</td><td>1,178</td></tr>
<tr><td>Therapy Services</td><td>1,897</td></tr>
<tr><td>Other</td><td>1,335</td></tr>
<tr><td>Total</td><td>21,160</td></tr>
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<tr><td>Alignment with IJB Strategic Objectives / Delivery Priorities</td><td>This Direction relates to the following strategic objectives outlined in the IJB Strategic Plan:

1. Develop services that are sustainable and proportionate to need
2. Deliver new models of community provision, working collaboratively with communities</td></tr>
</table>

	3. Focus on prevention and early intervention 4. Enable people to have more choice and control and provide care closer to home as appropriate 5. Further develop / embed integrated approaches and services 6. Keep people safe from harm 7. Address Health inequalities Within each of the Strategic Objectives there are a number of Strategic Delivery Priorities related to the services identified in this direction, with further details regarding these contained in the ELHSCP Annual Delivery Plan.
Compliance and performance monitoring	Performance will be monitored by review of the following: • National and local performance targets NHS Lothian is required to provide performance information to the IJB in relation to performance against local and national targets. NHS Lothian is also required to provide financial analysis, budgetary control, and monitoring reports as and when requested by the IJB. These reports should set out the financial position and outturn forecast against budget allocations by the IJB to NHS Lothian with respect to delivering hosted services.

Title of direction and reference number	**East Lothian Council delivery of social work and social care services – ref DC.4 (NEW)**
Date direction issued by IJB	TBC
Direction to	East Lothian Council
Does this direction supersede, amend, or cancel a previous direction? If yes, include reference number	Supersedes a number of Directions (reference numbers to be added)
Services / functions covered	This Direction covers social work and social care services delegated to East Lothian IJB as required by the Public Bodies (Joint Working) (Scotland) Act 2014 and outlined in East Lothian IJB's Integration Scheme. • Social work services for adults and older people • Services and support for adults with physical disabilities and learning disabilities • Mental health services • Drug and alcohol services • Adult protection and domestic abuse • Carers support services • Community care assessment teams • Support services • Care home services • Adult placement services • Health improvement services • Aspects of housing support, including aids and adaptions • Day services

	• Local area co-ordination • Respite provision • Occupational therapy services • Re-ablement services, equipment, and telecare • Criminal Justice Social Work services including youth justice
Full text of direction	East Lothian Council is directed to continue the provision of the services listed within current budgets detailed below and in accordance with any statutory / regulatory obligations where applicable and aiming to meet both national and local targets. Service development and delivery should be in line with East Lothian IJB's strategic objectives and strategic delivery priorities as laid out in its Strategic Plan for 2022-2025, as well as reflecting the key priorities contained in the East Lothian HSCP Commissioning Strategy for 2022-25. Services in the list above may be the subject of additional Directions where required in response to changing circumstances, including in response to service reviews, transformation programmes, strategic developments, or financial / budget changes.
Link to relevant IJB report	East Lothian IJB Strategic Plan 2022-25 East Lothian HSCP Commissioning Strategy 2022-25

<table>
<tr><td>Budget allocation from IJB to carry out direction</td><td>
<table>
<tr><th>Core Social Care Budget 2023/24</th><th>£,000</th></tr>
<tr><td>Adult Social Work</td><td>41,397</td></tr>
<tr><td>Acute & Ongoing Care</td><td>8,702</td></tr>
<tr><td>Rehabilitation</td><td>1,697</td></tr>
<tr><td>Adult Statutory Services U65</td><td>2,587</td></tr>
<tr><td>Statutory Services</td><td>2,360</td></tr>
<tr><td>Head of Operations</td><td>8,051</td></tr>
<tr><td>Business & Performance</td><td>3,159</td></tr>
<tr><td>Other</td><td>1,494</td></tr>
<tr><td>Total</td><td>69,447</td></tr>
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<tr><td>Alignment with IJB Strategic Objectives / Delivery Priorities</td><td>This Direction relates to the following strategic objectives outlined in the IJB Strategic Plan:

1. Develop services that are sustainable and proportionate to need
2. Deliver new models of community provision, working collaboratively with communities
3. Focus on prevention and early intervention
4. Enable people to have more choice and control and provide care closer to home as appropriate
5. Further develop / embed integrated approaches and services
6. Keep people safe from harm
7. Address Health inequalities

Within each of the Strategic Objectives there are a number of Strategic Delivery Priorities related to the services identified in this direction, with further details regarding these contained in the ELHSCP Annual Delivery Plan.</td></tr>
</table>

Compliance and performance monitoring	Performance in relation to delivering this Direction will be monitored by review of the following: • National and local performance targets • Milestones and performance measures outlined in East Lothian IJB's Annual Delivery Plan and reflected in the East Lothian HSCP Performance Framework East Lothian Council is required to provide performance information to the IJB in relation to performance against local and national targets and with respect to performance indicators contained in the ELHSCP Performance Framework. East Lothian Council is also required to provide financial analysis, budgetary control, and monitoring reports as and when requested by the IJB. These reports should set out the financial position and outturn forecast against budget allocations by the IJB to East Lothian Council with respect to delivering integrated health services.

Appendix 3 – East Lothian IJB Directions Template

Title of direction and reference number	
Date direction issued by IJB	
Direction to	
Does this direction supersede, amend or cancel a previous direction? If yes, include reference number	
Services / functions covered	
Full text of direction	
Link to relevant IJB report	
Budget allocation from IJB to carry out direction	
Which IJB Strategic Objectives / Delivery Priorities does the direction contribute to?	
Progress measures and timescales	

REPORT TO: East Lothian Integration Joint Board

MEETING DATE: 26 October 2023

BY: Chief Officer

7

SUBJECT: Integration Joint Board Member Code of Conduct and Responsibilities under the Ethical Standards Framework.

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1 PURPOSE

1.1 To inform new East Lothian Integration Joint Board (IJB) members and to update all other members regarding the Standards Commission for Scotland (SCS) model Code of Conduct, associated advice note for IJB members and the Ethical Standards Framework.

2 RECOMMENDATIONS

The IJB is asked to:

2.1 Note the requirement for the IJB to have in place a Code of Conduct to maintain compliance with the Ethical Standards in Public Life etc. (Scotland) Act 2000 and further note that the East Lothian IJB Code was revised and adopted in 2022.

2.2 Note the Chief Officer's role as Standards Officer for the IJB and the position's reporting, support and advisory duties.

2.3 Acknowledge the requirements placed on IJB members by the Code of Conduct and advice notes issued by the Standards Commission for Scotland

2.4 Ensure that individual members of East Lothian IJB sign the Code of Conduct and update their entry in the Register of Interests.

3 BACKGROUND

3.1 Integration Joint Boards (IJBs) were established in 2014 through the Public Bodies (Joint Working) Scotland Act as a means for health boards and local authorities to integrate adult health and social care services and budgets, through delegation to a locally accountable body.

3.2 East Lothian IJB was established in July 2015, taking on responsibility for development of integrated planning and delivery of health and social care services and criminal justice social work in the East Lothian Council geographical area, as well as certain acute hospital services managed by NHS Lothian.

3.3 All IJBs, as Devolved Public Bodies, must adopt a Code of Conduct to comply with the Ethical Standards in Public Life etc. (Scotland) Act 2000.

3.4 East Lothian IJB issued its first Code of Conduct in October 2015. This applied until the Standards Commission for Scotland developed a revised model Code in 2022, which the IJB subsequently adopted, with all members at that time signing the code to indicate acceptance.

3.5 The Code of Conduct reflects the nine key principles of public life in Scotland, which members of public bodies must adhere to. These cover:

- Duty
- Selflessness
- Integrity
- Objectivity
- Accountability and Stewardship
- Openness
- Honesty
- Leadership
- Respect.

3.6 The Code of Conduct states how its requirements should be applied in practice, provides illustrative case studies and sets out provisions for dealing with alleged breaches of the Code, including available sanctions on members.

3.7 The Standards Commission for Scotland has issued an Advice Note for members of Integration Joint Boards (Appendix 1). The Note:

- Provides members of IJBs *"…with an overview of their responsibilities under the ethical standards framework."*
- Emphasises that *"…members have a personal responsibility to observe the rules in their IJBs Code of Conduct…"* and reflects that the *"Advice Note is intended to assist [members] in interpreting the provisions in their IJB's Code of Conduct, and should, therefore, be read in conjunction with the Code."*
- Directs that the IJBs Code of Conduct *"…will apply in all situations, and at all times, where Members are acting as a member of the IJB, have referred to themselves as a member or could objectively be considered to be acting as a member."*
- Notes that Councillor or non-executive director IJB members should adopt an independent position in discharging their IJB role.
- Clearly delineates the strategic role of IJB members and its separation from the operational/service management role of the Chief Officer and HSCP Officers.

- Provides examples of potential breaches of the Code of Conduct, to assist members in judging where the code is at risk of being breached.
- Highlights the circumstances under which an IJB member might be sanctioned and/or disqualified.

3.8 The 2015 and 2022 Codes of Conduct recognise the Chief Officer as the Standards Officer for the IJB. The Standards Commission for Scotland (SCS) sets out the role of the Standards Officer in an Advice Note available at: www.standardscommissionscotland.org.uk/about-us/news/health-and-social-care-ijbs---standards-officer-appointments.

3.9 The duties of the Standards Officer cover:

- Regular training for IJB members on the ethical standards framework, the Code of Conduct and the Standards Commission guidance.
- Maintenance of high standards of conduct by promoting awareness of the Code and advising and supporting IJB members on its interpretation and application.
- Advising an individual member, if concerns arise they may have breached the Code, or risk doing so.
- To provide members with private advice or support (although, in some circumstances the Standards Officer may need to share information with other parties).
- To maintain an IJB Members' Register of Interests, updated at least yearly.
- To ensure each meeting of the IJB starts with a declaration of interest on any item/s on the agenda.
- In certain cases, to adopt an investigatory role in respect of complaints made or concerns raised about a member's conduct.
- To report to the IJB on matters relating to the Ethical Standards Framework and compliance.

3.10 The SCS also provides a suite of briefings regarding all aspects of the Code and public body and IJB member conduct. These are available at: www.standardscommissionscotland.org.uk/education-and-resources/professional-briefings.

4 ENGAGEMENT

4.1 There is no engagement required in connection with this paper.

5 POLICY IMPLICATIONS

5.1 There are no further policy implications, beyond ensuring all IJB members are aware of the Code of Conduct and associated guidance and have signed the Code and updated the Register of Interests.

6 INTEGRATED IMPACT ASSESSMENT

6.1 The subject of this report does not affect the wellbeing of the community or have a significant impact on equality, the environment or economy.

7 DIRECTIONS

7.1 There are no implications for Directions arising from this report.

8 RESOURCE IMPLICATIONS

8.1 There are no financial, personnel, or other resource implications arising from this report.

9 BACKGROUND PAPERS

9.1 The advice note for IJB members (also at appendix 1) is available at the Standards Commission for Scotland (SCS) website: www.standardscommissionscotland.org.uk/about-us/news/advice-note-for-members-of-ijbs

9.2 The SCS website also contains further information relevant to IJBs at: www.standardscommissionscotland.org.uk/search/?search-filter=ijb.

Appendix 1 – An Advice Note for IJB Members

Appendix 2 - A presentation regarding IJB Standards

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DATE	12 October 2023

Appendix 1

INTEGRITY IN PUBLIC LIFE

ADVICE FOR MEMBERS OF HEALTH AND SOCIAL CARE INTEGRATION JOINT BOARDS

1. Introduction

1.1 This Advice Note, issued by the Standards Commission, aims to provide members of Health and Social Care Integration Joint Boards (IJBs) with an overview of their responsibilities under the ethical standards framework. It seeks to assist members in recognising and dealing with potential conflicts of interest to minimise the risk that such a conflict will erode effective governance and scrutiny arrangements.

1.2 Members have a personal responsibility to observe the rules in their IJBs Code of Conduct, which is based on the revised Model Code of Conduct issued by the Scottish Ministers in December 2021. This Advice Note is intended to assist them in interpreting the provisions in their IJBs Code of Conduct, and should, therefore, be read in conjunction with the Code. The Standards Commission's Guidance on the Model Code of Conduct for Members of Devolved Public Bodies also provides advice on how the relevant provisions in the Code should be interpreted.

1.3 The IJBs Code of Conduct will apply in all situations, and at all times, where Members are acting as a member of the IJB, have referred to themselves as a member or could objectively be considered to be acting as a member. In determining whether the Code applies, the Standards Commission will consider whether a member of the public, with knowledge of the relevant facts, would reasonably consider that you were acting as a member of the IJB at the time of the events in question.

1.4 All IJBs are required to appoint a Standards Officer, with the appointment then being approved by the Standards Commission. The Standards Commission's Advice Note on the Role of a Standards Officer provides information on a Standards Officer's role and responsibilities, within the ethical standards framework, and the duties they may be expected to discharge. These can include ensuring that appropriate training is given to IJB members on the ethical standards framework, the IJB's Code of Conduct and the Standards Commission's Guidance. The Standards Officer can also provide advice and support to members on the interpretation and application of the IJB's Code.

1.5 Some examples of potential breaches of the Code have been included at Annex A, to assist members in relating the provisions to scenarios they may face or situations they may find themselves in.

1.6 It should be noted that the Public Bodies (Joint Working) (Integration Joint Boards) Scotland Order 2014 provides, at paragraph 8(3), that an individual will be automatically disqualified from being a member of an IJB if they have been subject to a sanction under section 19(1)(b) to (e) of the Ethical Standards in Public Life etc. (Scotland) Act 2000 (2000 Act). The Health Boards

(Membership and Procedure) (Scotland) Amendment Regulations 2016 contains an analogous provision, at paragraph 2(5)(j), for members of health boards. This means that if the Standards Commission, at a Hearing, imposes any sanction, other than a censure, on any individual under Section 19 of the 2000 Act for a breach of a Code of Conduct of any organisation within its remit (including local authorities, IJBs, health boards and other public bodies), that individual will be disqualified from being a member of any IJB or health board, without limit of time.

2. Background

2.1 The Standards Commission's functions are provided for by the 2000 Act. The 2000 Act created an ethical standards framework under which councillors and members of devolved public bodies are required to comply with Codes of Conduct, approved by the Scottish Ministers, together with Guidance issued by the Standards Commission.

2.2 The role of the Standards Commission is to:

- encourage high ethical standards in public life; including the promotion and enforcement of the Codes of Conduct and to issue guidance to councils and devolved public bodies; and
- adjudicate on alleged breaches of the Codes of Conduct, and where a breach is found, to apply a sanction.

2.3 The Public Bodies (Joint Working) (Scotland) Act 2014 required councils and NHS boards to work together to form new partnerships, known as Integration Authorities, to ensure health and social care services are well integrated.

2.4 Boards of IJBs comprise of a mix of voting and non-voting members. Councils and NHS boards are each required to nominate at least three voting members, with the number from each body being equal (NHS boards nominate non-executive directors to the IJB and councils nominate councillors). IJBs also include non-voting members, including a service user and a representative from the voluntary sector, albeit the voting members are exclusively members from councils and NHS boards.

2.5 IJB members are responsible for overseeing IJBs and scrutinising performance to ensure that they are being properly run, with all funds being used appropriately and in accordance with best value principles. Councillor and health board members can inform the IJB about the council's and health board's policies and priorities. However, when acting as members of an IJB, councillors and health board members have a duty to act in the best interests of that IJB and not the body which nominated or appointed them. Councillors and health board members sitting on IJBs nevertheless have legal obligations and responsibilities to their council or health board as well as to their IJB. There is, therefore, the potential for conflicts of interest and any associated risks to effective governance and scrutiny to arise. This Advice Note is intended as an additional resource to support the existing guidance for IJB members to help them identify and manage such conflicts and risks.

3. Understanding the IJBs Role and Responsibilities

3.1 IJBs direct their respective NHS board and council to deliver services, meaning NHS boards and councils are accountable to IJBs for the delivery of services as directed, with IJBs being accountable for overseeing the delivery of services.

3.2 Both NHS boards and councils delegate specific services to the IJB and provide money and resources. IJBs are then responsible for planning health and care services and have full powers to decide how to use resources and deliver delegated services to improve quality and outcomes. IJBs are jointly accountable to their respective councils and NHS boards through their voting membership and reporting to the public. Integration is intended to shift the focus from what

worked for organisations, to what works for individuals who require health and social care services.

4. Understanding Your Role & Responsibilities

4.1 IJBs include representatives from councils, NHS boards, GPs, the voluntary sector, and service users. You should ensure that you understand, respect and take account of differences in organisational cultures so these do not become a barrier to progress and to the effectiveness of the IJB.

4.2 It is important for IJBs to ensure governance and accountability in respect of both finance and performance. If you are nominated, appointed or otherwise agree to sit on an IJB, you will need to be aware of your obligations to the IJB and reconcile these with your obligations to other bodies you are associated with, such as your council, NHS board (if you are a councillor or member of a health board) or political group. You should ensure that you are fully aware of the IJB's purpose, structure and strategic aims. You should also ensure you understand the functions it performs and the activities it undertakes.

4.3 It is also important to have knowledge of the funding arrangements for the IJB, including the level of funding provided by the council and health board. You should be satisfied you are aware of the IJB's financial monitoring and reporting arrangements and also its approach to risk.

4.4 The design of IJBs brings the potential for real or perceived conflicts of interest for board members. The NHS board and council nominate all voting members of the IJB. Their role is to represent the IJB's interests. Voting members will also continue in their role as an NHS board member or councillor. As a result, there is a risk that they may have a conflict of interest, particularly where there is a disagreement between the council and a health board with regard to IJB business, including the money and resources the council and health board are providing to the IJB. As an IJB member, you will have to manage any such conflicts of interest.

4.5 There is also a particular risk of conflict for councillor and NHS board members in that they may be acting as IJB board members while commissioning a service, but also for the Council or the NHS board which is then responsible for delivering and evaluating that service.

4.6 The purpose of the Codes of Conduct is to ensure that IJB board members adhere to the same standards of behaviour. You should ensure that you are familiar with the provisions in the Code and that you comply with them at all times when you are acting, or could be reasonably regarded as acting, as a member of the IJB.

4.7 In most cases your duty under the Code to act in the public interest will align with your duty to act in the best interests of the IJB. Where there is a conflict, however, you should assess whether you are required to declare an interest and whether you should withdraw from the discussion and decision-making (see Section 8 below).

4.8 You should be aware that, as a member of the IJB, you must act in its best interests when acting as such, regardless of whether you have been appointed or nominated to it from a Council, health board or other organisation. While you can raise matters from the perspective of an outside organisation, you should not promote the interests of, or lobby on behalf of, an outside body when sitting as an IJB member. It is, therefore, essential that you have clear understanding of the roles and responsibilities of each body you are on and that you are required to act in the best interests of the one you are representing at any given time.

4.9 If you are a councillor member of the IJB, you should be aware that the Councillors' Code of Conduct makes it clear that you still need to observe the rules in the Councillors' Code even while carrying out your duties as a member of an IJB. You will also be bound by the rules of

conduct for the IJB and are also responsible to the IJB and are required to act in its best interests. This obligation is outlined in Paragraph 3.30 of the Councillors' Code, which states:

> If I am appointed, or nominated by the Council as a member of another body or organisation, I will abide by the rules of conduct and will act in the best interests of that body or organisation while acting as a member of it. I will also continue to observe the rules of this Code when carrying out the duties of that body or organisation.

4.10 Similarly, if you are a health board member of the IJB, you should be aware that the Health Board's Code of Conduct makes it clear that you still need to observe the rules in that Code even while carrying out your duties as a member of an IJB. You will also be bound by the rules of conduct for the IJB and are also responsible to the IJB and are required to act in its best interests. This obligation is outlined in the provisions on 'Appointments to Outside Organisations' in Section 3 of the Model Code, which state:

> If I am appointed, or nominated by my public body, as a member of another body or organisation, I will abide by the rules of conduct and will act in the best interests of that body or organisation while acting as a member of it. I will also continue to observe the rules of this Code when carrying out the duties of that body or organisation.

4.11 If you are a councillor or health board member of the IJB, you should be mindful that the requirement to act in the interests of the IJB while carrying out your duties as a member of it may require you to make decisions that could potentially be inconsistent with, or diverge from, the priorities or stated aims of the Council, Health Board or any political party you represent.

4.12 You should make sure you are clear about the status of your appointment and whether you are on the IJB board as a voting or non-voting member. If you are a proxy or substitute member, you should be aware that you are only entitled to attend any meeting of the IJB if the member for whom you have the proxy or are a substitute for is unable to be present.

4.13 Audit Scotland's 'Health and social care integration' and 'Health and social care integration: Update on progress' reports both recommend that IJB members should be provided with training and development to prepare them for their role. The reports recommend that the training should cover managing conflicts of interest, understanding the organisational cultures of the NHS and councils and the roles of non-voting members of the IJB. You should, therefore, ensure that you have undertaken this training after accepting any nomination to an IJB. You may also wish to refer to the Scottish Government's 'On Board: a guide for members of statutory boards' and the 'Role, Responsibilities and Membership of the Integration Joint Board' guidance, which outline some helpful principles for roles on boards in general and for membership of an IJB. You should consider providing feedback on any training or induction you receive to help ensure it remains effective and relevant.

4.14 The table below summarises the information you should be aware of before accepting an appointment or nomination to sit on an IJB.

The composition of the IJB.
The IJB's purpose, structure, strategic aims and the activities it undertakes.
The IJB's funding, financial monitoring and reporting arrangements.
That you will be obliged to act in the best interests of the IJB while acting as a member of it.
The potential for conflicts of interest to arise.
The IJB's Code of Conduct.
Your status on the IJB.

5. Culture of Respect

5.1 You should behave in accordance with the IJB's Code in all situations where you act as an IJB member or are perceived as acting as such, including representing it on official business and when using social media.

5.2 You should ensure that you are familiar, and comply, with the terms of any policy your IJB has issued on dignity in the workplace.

5.3 You must treat all individuals with courtesy and respect when carrying out your duties as an IJB member. You should not participate in, or condone, acts of harassment, discrimination, victimisation or bullying. This can include, but is not limited to:

- unwelcome physical, verbal or non-verbal conduct;
- intimidatory behaviour including verbal abuse or the making of threats;
- making someone's working life difficult;
- disparaging, ridiculing or mocking comments and remarks;
- deliberately excluding an individual from conversations, work or social activities, in which they have a right or legitimate expectation to participate; and
- ignoring a fellow Member's contribution to a debate, talking over them or being dismissive of their views.

You may wish to have regard to the Standard's Commission's standalone Advice Note on Bullying and Harassment.

5.4 You should be aware of the inherent influence your role brings and ensure that you are demonstrating respect for others and encouraging colleagues to do the same.

5.5 As noted above, you should ensure that you are aware of the composition of the IJB board and the value that having input and perspective from representatives of different bodies, organisations and sectors will bring to determining how local services can be improved. You can demonstrate this by ensuring that you listen to, and take account of, the views of other members.

5.6 You should also be aware of the role that officers play and ensure you are not compromising this by behaving in a manner that could result in them feeling threatened or intimidated, which in turn could prevent them from undertaking their duties properly and appropriately. You must not bring any undue influence to bear on an officer to take a certain action, particularly if it is contrary to the law or the IJB's policies and procedures.

5.7 In dealing with officers and members of the public, you should always consider both what you are expressing and the way you are expressing it. You should also consider how your conduct could be perceived. You should be able to undertake a scrutiny role and make contributions to discussions and debates in a constructive, respectful, courteous and appropriate manner without resorting to personal attacks, being offensive, abusive and / or unduly disruptive.

5.8 You have a right to high quality information and are entitled to seek further information to enable you to undertake your scrutiny role effectively. You are entitled to challenge officers and colleagues, but you must not do so in a personal or offensive manner.

5.9 As a member, your role is to determine policy and to participate in decisions on matters placed before you. It is not to engage in direct operational management of the IJB. You should bear in mind that any issues relating to behaviour, performance or conduct of an officer should be raised privately with the appropriate senior manager.

5.10 As someone in a position of trust, you may be made aware of incidents that are brought to your attention by victims of inappropriate behaviour, or other witnesses. You can assist by becoming familiar with what is meant by harassment, discrimination, victimisation and bullying and the impact these can have on individuals or groups.

5.11 If you are a witness to any acts of bullying, harassment, discrimination or victimisation, you should encourage the victim to seek support and assistance and make it clear that you will offer them assistance and provide evidence if they decide to make an informal or formal complaint.

5.12 Where you have witnessed bullying, harassment, discrimination or victimisation you have a responsibility to speak out. You should challenge inappropriate behaviour as it happens and consider making a complaint.

5.13 You should be mindful that there can be differences in culture between organisations. For example, behaviour that may be accepted as part and parcel of robust political debate on a Council may be perceived as being unacceptably negative or unhelpful on an IJB.

5.14 You should also be mindful of how you could be perceived, as a member of an IJB, when using social media. The Standards Commission has produced an Advice Note for members of devolved public bodies (which includes IJBs) on the use of the use of social media.

6. Decision-Making

6.1 Unlike the Codes for members of other devolved public bodies, the Codes for members of IJBs do not contain a requirement to respect the principle of collective responsibility. IJBs may take decisions on difficult issues and, as such, members may have genuine and strongly held differences of opinion. Once issues are thoroughly debated, however, decisions should be taken, and the majority vote should prevail. As a member, you will have to decide whether to support the decision, and if not, whether you wish to have your dissent formally recorded. You should note that continuing with a conflict, when it has become apparent that other members will not change their minds, can waste time and be demotivating and futile.

6.2 You should bear in mind that while issues can and should be debated robustly, if you express division outside the boardroom by, for example, talking to the media or officers or posting on social media, stakeholders can lose confidence in the organisation. This is because confidence and trust can be eroded if a board is perceived as being divided, with its members criticising each other.

7. Registration of Interests

7.1 It is your personal responsibility to ensure your Register of Interests is accurate and up to date. You must ensure any changes are made within one month of your circumstances changing (see the Ethical Standards in Public Life etc. (Scotland) Act 2000 (Register of Interests) Amendment (No. 2) Regulations 2021.

7.2 The IJB's Code of Conduct will state the interests, financial and otherwise, that you are required to include in your Register of Interests. If you are unclear about how much information to include in your Register of Interests, you can also seek advice from the Standards Officer or the Standards Commission.

7.3 You should bear in mind that what you are required to register in the IJB's Register of Interests and what you are required to declare may be different. You should seek advice if you are unclear about what is required. You should note that you cannot remedy a failure to register a financial or non-financial interest by declaring it.

7.4 If you are a councillor, health board member or member of another devolved public body, you should, in particular, consider whether you need to register an interest under Categories 1 (Remuneration) and 8 (Non-Financial Interests).

8. Identifying Potential Conflicts of Interest and Making Declarations of Interest

8.1 The public must have confidence that members of IJBs are taking decisions in the public interest and not for any other reason. It is essential, therefore, that you are transparent about any interests which could influence, or could be considered as being likely to influence, your discussion and decision-making as a member of the IJB.

8.2 You should ensure that you can identify potential conflicts of interest. These will include not just the potential for competing interests between the IJB and your council or health board (if applicable) and also any other organisation you are a member of, but also any personal interests you may have.

8.3 In considering whether to declare an interest in any item before your IJB, you must consider the objective test at paragraph 5.5 of the Code which is whether:
a member of the public with knowledge of the relevant facts would reasonably regard your connection to a particular matter as being so significant that it would be considered as being likely to influence the discussion or decision-making
In applying the objective test, you should always err on the side of caution.

8.4 You must declare any relevant interest and withdraw from the room while the item is being considered, discussed, and voted upon. It is not sufficient for you to retire to the back of the room or any public gallery. If the meeting is being held online, you should retire to a separate breakout room or leave and re-join after the discussion on the matter has concluded. It is not sufficient for you to turn off your camera and / or microphone for the duration of the matter. This is to avoid giving rise to any perception that you are still in a position to influence the outcome of the deliberations on the item.

8.5 You should be aware that the categories of interest that can require a declaration include both your own personal financial and non-financial interests (including as a member of another body, or organisation, such as a society, club or charity).

An example of a declarable non-financial interest might be if you were a GP and the IJB was being asked to approve plans to implement the Scottish General Medical Services contract.

8.6 Categories of interest that can require a declaration can also include the financial and non-financial interests of other persons and bodies. Other persons and bodies can include your friends and family, employer and a body of which you are a member.

An example of a declarable interest concerning another person or body might be if the IJB was being asked to approve funding to an organisation and your partner was an employee of the organisation.

8.7 You should not rely on, or expect, officers to remind you to make declarations even if you think they are aware of your interests, including any membership of another organisation. It is solely your own personal responsibility to make declarations of interest as required. If you are in any doubt, you should ask for help from the Chair or Standards Officer.

8.8 You should consider whether agendas for meetings raise any issues of declaration of interest and, if so, you should make your declaration of interest as early as possible at a meeting where that interest arises. If you do identify the need for a declaration of interest only when a particular matter is being discussed, you must declare the interest as soon as you realise it is necessary.

8.9 You should begin your statement with the words "I declare an interest" and identify the item or items of business to which it relates. You do not need to give a detailed description of the interest, but your statement must contain sufficient information to enable those present to understand the nature of it.

8.10 The Standards Commission has produced an Advice Note for members on how and when to declare an interest at meetings. The Advice Note suggests wording that members may wish to consider using when declaring an interest.

8.11 If accepting an appointment on an IJB would mean you would have to declare interests frequently, you should carefully consider whether it is appropriate to accept the appointment.

8.12 The table below summarises the questions you should consider when identifying potential conflicts of interest and making declarations of interest.

Have I registered my interests as required by the Code? If my circumstances have changed, have I updated my register?
What are the potential conflicts between the IJB and any other body I am a member of or sit on?
Have I checked the meeting agenda to determine whether I will need to make any declarations of interest?
Do I have any personal interests, either financial or non-financial in the matters being discussed?
Does any individual, body or organisation I am connected to have any financial or non-financial interests in the matters being discussed?
Have I applied the objective test? Have I considered whether any interest I have could be perceived as being sufficiently significant that it could reasonably be taken to fall within the test?
Will I be making regular declarations of interest?

9. Confidentiality

9.1 If you are a member of an outside organisation, including a council or health board, you may have access to information that should not be disclosed to both the outside organisation and the IJB. As such, you should be aware of the following confidentiality requirements outlined at paragraphs 3.22 to 3.25 of the Model Code, which are as follows:

3.22 I will not disclose confidential information or information which should reasonably be regarded as being of a confidential or private nature, without the express consent of a person or body authorised to give such consent, or unless required to do so by law. I note that if I cannot obtain such express consent, I should assume it is not given.

3.23 I accept that confidential information can include discussions, documents, and information which is not yet public or never intended to be public, and information deemed confidential by statute.

3.24 I will only use confidential information to undertake my duties as a board member. I will not use it in any way for personal advantage or to discredit my public body (even if my personal view is that the information should be publicly available).

3.25 I note that these confidentiality requirements do not apply to protected whistleblowing disclosures made to the prescribed persons and bodies as identified in statute.

9.2 This means that if you were provided with confidential information, such as information disclosed in a closed or private section of an IJB meeting or legal advice obtained by the IJB (either from officers or external legal advisers), you should not disclose or release it to the

council or health board or to any other outside body or individual even if it concerns that body. If such a case were to arise, you should raise the matter with the IJB's Standards Officer.

9.3 If you are in any doubt about whether information is confidential, you should seek advice from the Standards Officer.

10. Training and Assistance

10.1 You should obtain training on your role from the IJB when appointed and should also attend any ongoing or refresher training in respect of your role as a member.

10.2 You can also contact the Standards Commission via email: enquiries@standardscommission.org.uk.

11. Sources of Information

11.1 Further sources of information you may find to be of assistance are listed in the table below.

Publication	Issued By
Report: Health and social care integration: update on progress	Audit Scotland
On Board: a guide for members of statutory boards	Scottish Government
Advice for Members on How to Declare Interests	Standards Commission
Advice on the use of Social Media for Members of Devolved Public Bodies	Standards Commission
Role, Responsibilities and Membership of the Integration Joint Board guidance	Scottish Government
Report: Health and social care integration	Audit Scotland
The Role of Boards	Audit Scotland
Registration of Interests Regulations 2021	Scottish Statutory Instrument

ANNEX A: CASE EXAMPLES

Respect

You have noted that the Chair of your IJB routinely ignores the contribution of the carer representative and allows councillor members of the IJB to speak over him. At the last meeting of the IJB, a councillor member told the carer representative to "shut up" when he tried to object to a proposal being considered. The carer representative advised you that he considers he is being side-lined as the Chair has recently held meetings with the substitute carer representative about IJB business, but has not invited him. The carer representative is considering resigning as he feels unable to contribute properly. He considers there may have been a breach of the Code by the Chair and others. Could he be right?

Yes. The representative is on the IJB to provide input on local services from his perspective as a carer and he should be encouraged to do so. The Chair should be reminded of the inherent influence their role brings and should ensure that not only are they demonstrating respect for all members of the IJB, but that they are also encouraging colleagues to do the same. The Chair and councillor members are not demonstrating respect if they are not listening to, and taking account of, the views of the carer representative or if they are being rude to him. It should be noted that bullying can be a pattern of behaviour or can be a one-off incident that is objectionable or intimidating. It can include deliberately excluding an individual from conversations or meetings, in which they have a right or legitimate expectation to participate.

You have a responsibility to speak out and challenge the inappropriate behaviour. You should also remind the Chair that the substitute member should only be invited to attend and participate at a meeting if the carer representative has been invited but is unable to attend. You should encourage the carer representative to remain on the board and seek to engage him in its discussions.

Respect

You are being asked to approve a strategic plan, drafted by officers, to redesign the learning disability services in your area. You are concerned that inadequate consideration has been given to transportation and that users and families may require to travel longer distances to access services under the changes proposed. Can you raise concerns about this?

Yes. You have a right to high quality information and to scrutinise and challenge recommendations and proposals. You are entitled to challenge the adequacy of the report and its conclusions, and to ask for further work to be undertaken or additional information to be provided, provided you do so in a respectful, courteous and appropriate manner. You are not entitled to be offensive, abusive and / or unduly disruptive, or to raise any matters concerning the conduct or capability of officers in public. You should be mindful of your tone and choice of language to ensure that you are being courteous and respectful when asking for further work to be undertaken or information provided.

Confidentiality

You are a councillor representative on an IJB. You have just been told that a proposal to close a significant number of care of the elderly beds within a hospital in your ward, in order to invest in alternative community-based models of care, is to be considered at the next meeting of the IJB. You are concerned that people using care, their families and staff at the hospital in question have not been consulted on the proposed changes. You want to draw the matter to their attention so that their views are sought before a decision is taken. You consider the best way to do that would be to contact the local media to alert them to the proposal. Can you do so?

No, if the proposal is not yet in the public domain and /or the intention is for it to remain confidential for the time-being. You could potentially be in breach of the confidentiality provisions in the Code by divulging anything about the proposal without having first checked whether information relating to it should be kept private. You should note that it may be that a plan to consult with those who could be directly affected by the proposal is to be discussed as part of the board's consideration of the matter.

Registration of Interests

You are aware that a councillor member of your IJB works for an MSP on a part-time basis. They have registered the employment with the Council and have openly discussed it on social media. The councillor member recently declared an interest in a proposal being considered by the IJB and took no part in the discussion and decision-making, as the MSP they work for has been vociferous in the media about their opposition to the proposal. You have noted, however, that they have not registered the employment on the IJB's register of interests. Does this matter?

Yes. If the employment is remunerated, it must be registered (within one month). The member does not need to state the amount of their salary, but must provide the name of the employer, nature of business and nature of the post they hold. The fact that the member has registered the employment with the Council and has been open about it on social media is not relevant to the question of whether they have complied with the provisions in the IJB's Code. This is because the purpose of having a register is to provide information to the public about the interests of members which might influence their judgement, decision making and actions, or which might be perceived by a reasonable member of the public as doing so. Members of the public might only check the IJB's register of interests, not the Council's one. They may not access or see any postings on social media, or the minute of the meeting in question. Declaring a registerable interest will not remedy any failure to register it, as the fact that a member has declared an interest in one particular item does not necessarily preclude the possibility that they should have done so in respect of another similar or even entirely unconnected matter.

Declarations of Interest

Your IJB is being asked to approve expenditure to support implementation of the area's Primary Care Improvement Plan. Your parents are patients of a GP Practice in the area. Are you obliged to declare this as an interest?

No. It is unlikely that a member of the public, with knowledge of your family's connection to the area and likelihood that they might be patients of a GP practice within it, would reasonably regard your interest as so significant that it would be likely to prejudice your discussion or decision-making. This is because the Primary Care Improvement Plan would cover all primary care services and would have an impact on all GP Practices in the area, not just the one in question.

Declarations of Interest

Your IJB is being asked to consider a report seeking approval for the implementation of a programme to support the further integration of learning disability services in the area. The report recommends that the IJB board approve the implementation of the proposed programme, including expenditure and the award of a contract to a preferred service provider. Your partner works for a similar service provider in the area and has advised you that the decision could potentially lead to some job losses within his organisation. His own role may be under threat of redundancy. Should you declare an interest?

Yes. You are obliged under the Code to declare both the financial and non-financial interests of partners, close relatives and close friends, if the interest is sufficiently significant that it could be taken to fall within the objective test. In this case, your partner would have a non-financial interest (that is likely to be considered significant), by virtue of his employment at a potential competitor. The fact that his

employment could be affected by the decision would make it also a financial interest. It is likely that a member of the public, with knowledge of your partner's job, would reasonably regard your interest as so significant that it would be likely to prejudice your discussion or decision-making. You should declare an interest and withdraw from the room while the matter is being discussed and any decisions are being made.

Conflict of Interest

You are a councillor member of an IJB. The IJB is to consider a plan to decommission respite services currently delivered at a unit in your constituency ward. You understand that the proposal will ensure best value and consider it to be appropriate in terms of modernising interventions and services in the overall region. You are aware, however, that there is support for retaining the unit amongst your constituents, who consider that it provides an essential local service for carers and the elderly. How do you reconcile your roles and the different considerations?

You are obliged under the IJB's Code to act in its best interests while carrying out your duties as a member of it. As such, when considering the plan, you must base your decision on the interests of the IJB, even if these are inconsistent with what you think may be the interests of your ward constituents.

Decision Making

You are a third sector representative on an IJB. At its last meeting, the IJB considered a proposal to direct the local Council to cut funding for a drug dependency support service. You are concerned about the scale of job losses, the short timescales for the closure of the service and the overall impact it will have on drug users in the area. Other members of the IJB are content with reassurances from officers that an impact assessment and subsequent risk mitigation plan will be put in place, and that the funding cut will result in savings that will help deliver efficiency and innovation in respect of other analogous services. You simply cannot accept that the funding cut is necessary or appropriate, however, as you have heard many accounts of the benefits that the service provides. What can you do?

You can ask for your dissent to be recorded in the minutes of the meeting, if you remain unhappy. Ultimately, however, if the decision is legal and was made in accordance with the IJB's standing orders, policies and procedures then it is legitimate, regardless of your opinion. You either need to accept that or consider whether you wish to remain as a member of the IJB. You could be in breach of the Code if, outside the boardroom, you publicly criticise officers or make disrespectful comments about other members. This would include when you are posting on social media.

East Lothian Health & Social Care Partnership

IJB Standards

Integration Joint Boards

- Integration Joint Boards (IJBs) were established in 2014 as a means for health boards and local authorities to integrate adult health and social care services and budgets, through delegation to a locally accountable body.
- East Lothian IJB was formally established in July 2015, taking on responsibility for development of integrated planning and delivery of health and social care services and criminal justice social work in the East Lothian Council geographical area, as well as certain acute hospital services managed by NHS Lothian.
- East Lothian IJB issued its first Code of Conduct in October 2015. This applied until the Standards Commission for Scotland developed a revised model Code in 2022, which the IJB subsequently adopted.
- The 2015 and 2022 Codes of Conduct recognise the Chief Officer as the Standards Officer for the IJB. The Standards Commission sets out the role of the Standards Officer in an Advice Note.

Standards Officer Role

- To ensure IJB members receive appropriate training (on induction and regularly thereafter) on the ethical standards framework, the Code of Conduct and the Standards Commission guidance.
- To contribute to the maintenance of high standards of conduct by promoting awareness of the Code and advising and supporting IJB members on its interpretation and application.
- To advise a member if concerns arise that the member may have breached the Code, or risks doing so.
- To make members aware that advice or support is available in private (although the Code treats any advice as confidential, in some circumstances the Standards Officer may need to share information with other parties).
- To ensure a Members' Register of Interests is maintained, with entries updated at least yearly, and to ensure each meeting of the IJB starts with a declaration of interest on any item/s on the agenda.
- To adopt an investigatory role in some cases, in respect of complaints made or concerns raised about a member's conduct.
- To report to the IJB on matters relating to the Ethical Standards Framework and compliance.

IJB Code of Conduct

- All IJBs, as Devolved Public Bodies, are required to adopt a Code of Conduct to comply with the Ethical Standards in Public Life etc. (Scotland) Act 2000.
- East Lothian IJB approved a revised Code of Conduct in June 2022 with all existing members and future members required to sign the Code to indicate acceptance.
- The Code of Conduct was based on a Model Code, developed by the Standards Commission for Scotland. The Commission also provides a suite of briefings regarding all aspects of the Code and IJB member conduct (www.standardscommissionscotland.org.uk/education-and-resources/professional-briefings).
- The Code of Conduct reflects the nine key principles of public life in Scotland (listed below).
- The Code states how its requirements should be applied in practice and sets out provisions for dealing with alleged breaches of the Code, including the sanctions that can be applied.

Nine Principles of Public Life (1/2)

Duty - I have a duty to uphold the law and act in accordance with the law and the public trust placed in me. I have a duty to act in the interests of the East Lothian IJB of which I am a member and in accordance with the core functions and duties of the IJB.

Selflessness - I have a duty to take decisions solely in terms of public interest. I must not act in order to gain financial or other material benefit for myself, family or friends.

Integrity - I must not place myself under any financial, or other obligation to any individual or organisation that might reasonably be thought to influence me in the performance of my duties.

Objectivity - I must make decisions solely on merit and in a way that is consistent with the functions of the IJB when carrying out public business. including making appointments, awarding contracts or recommending individuals for rewards and benefits.

Nine Principles of Public Life (2/2)

Accountability and Stewardship - I am accountable to the public for my decisions and actions. I have a duty to consider issues on their merits, taking account of the views of others and I must ensure that the IJB uses its resources prudently and in accordance with the law.

Openness - I have a duty to be as open as possible about my decisions and actions, giving reasons for my decisions and restricting information only when the wider public interest clearly demands.

Honesty - I have a duty to act honestly. I must declare any private interests relating to my public duties and take steps to resolve any conflicts arising in a way that protects the public interest.

Leadership - I have a duty to promote and support these principles by leadership and example, and to maintain and strengthen the public's trust and confidence in the integrity of the IJB and its members in conducting public business.

Respect - I must respect all other board members and all employees of the IJB and the role they play, treating them with courtesy at all times. Similarly, I must respect members of the public when performing my duties as a board member.

Strategic Role and Operational Work

The Standards Commission notes that the role and work of a public body is *"…balanced with, and complemented by, the role and work of employees."*

Public Body members determine policy and scrutinise the organisation's performance against its strategic aims, with each member contributing to:

- Providing strategic leadership;
- Ensuring the public body meets its strategic aims and statutory obligations;
- Ensuring the public body puts the needs of its service users at the forefront of any decision making;
- Holding the Chief Executive and senior management team to account by scrutinising the way in which services are delivered and the implementation of policies and procedures;
- Making or approving decisions that are key to how the public body operates; and
- Ensuring financial stewardship is achieved through the efficient, economic and effective use of resources.

Strategic Role and **Operational Work**

- Guidance suggests that an IJB Member's role in scrutiny should focus on making recommendations for improvement and *"…should not normally be used to direct, instruct or pressure an individual employee to make or change a specific operational decision."*
- There are exceptions, to reflect circumstances in which operational matters have strategic implications concerning how the IJB should *"…deploy its resources and/or ones that carry a significant risk to the status or reputation of the public body, or its ability to provide services effectively."*
- It is noted that some decisions may have *"…both operational and strategic elements, particularly if they concern expenditure that does not fall within existing budgets."* Such "…*decisions may be taken jointly by members and employees; or by employees following consultation with certain members (such as members of an Audit & Risk or Human Resources Committees)."*

Strategic Role and **Operational Work**

- Members may be required to become involved in operational management or decision-making because of: their letter or contract of appointment; a statutory provision; on invitation from the public body's Chair; and/or having been directed to do so by their sponsor body, Minister or Cabinet Secretary.
- Examples of the above may include making decisions on:
  - casework or complaints;
  - regulatory or quasi-judicial applications; and
  - the appointment of senior employees.
- Members taking on any operational decision-making role, must be clear on *"…what it will involve and.. understand how to identify, and appropriately manage, any conflicts of interest.*
- It is acknowledged that it may on occasion be difficult for members to *"…distinguish between operational and strategic matters and to understand the extent to which they should get involved."* At such times, it may assist to seek guidance from the Standards Officer.

Public Body Members Advice Notes

The Standards Commission for Scotland provides Members Advice Notes on:

- Distinguishing Between their Strategic Role and any Operational Work.
- Bullying and Harassment.
- How to Declare Interests.
- Social Media.
- Role of a Standards Officer.
- Relations Between Members and Employees.
- Members of Health and Social Care Integration Joint Boards.
- Gifts and Hospitality.
- Conduct During Online Meetings.
- Summary of Article 10 European Convention on Human Rights (ECHR).

Advice Note for IJB Members

The specific Advice Note issued for members of Integration Joint Boards:

- Provides members of IJBs *"…with an overview of their responsibilities under the ethical standards framework."*
- Emphasises that *"…members have a personal responsibility to observe the rules in their IJBs Code of Conduct…"* and reflects that the *"Advice Note is intended to assist [members] in interpreting the provisions in their IJB's Code of Conduct, and should, therefore, be read in conjunction with the Code."*
- Directs that the IJBs Code of Conduct *"…will apply in all situations, and at all times, where Members are acting as a member of the IJB, have referred to themselves as a member or could objectively be considered to be acting as a member."*
- Provides examples of potential breaches of the Code, to assist members in judging where the code is at risk of being breached.
- Highlights the circumstances under which an IJB member might be sanctioned and/or disqualified.

Other IJB Considerations

- All IJB members need to ensure their entries in the 'Register of Interests' are kept current and that they provide a declaration of interest at the beginning of all IJB meetings.
- Councillor or non-executive director IJB members should adopt an independent position in discharging their IJB role.
- Although the majority of IJB decisions are reached by consensus, there are occasions where a vote is required for specific items. In making a decision on how to vote, IJB members should ensure they are fully and objectively informed on all aspects of the matter under consideration and act in the interest of the IJB.
- Members should familiarise themselves with the Revised Joint Integration Scheme 2023 for East Lothian, which took effect from 15th May 2023, following approval by Scottish Ministers.

Case Studies

Declarations of Interest

Your IJB is considering a report seeking approval for a programme to support the further integration of learning disability services in the area. The report recommends that the IJB approve the award of a contract to a preferred service provider. Your partner works for a similar service provider in the area and has advised you that the decision could potentially lead to some job losses within his organisation, and his own role may be under threat. Should you declare an interest?

Yes. You are obliged under the Code to declare the financial and non-financial interests of partners, close relatives and close friends, if the interest is sufficiently significant that it could be taken to fall within the objective test.

In this case, your partner would have a non-financial interest (that is likely to be considered significant) by virtue of his employment by a potential competitor. There is also a financial interest, as his employment could be affected by the IJB decision. It is likely that a member of the public, with knowledge of your partner's job, would reasonably regard your interest as so significant that it would be likely to prejudice your decision-making.

You should declare an interest and withdraw from the room/close the MS Team link while the matter is being discussed and any decisions are being made. After this is you may re-join the meeting.

Case Studies

Decision Making

You are an IJB third sector representative. At its last meeting, the IJB considered a proposal to direct the local Council to cut funding for a drug dependency support service. You are concerned about the scale of job losses, the short timescales for the closure of the service and the overall impact it will have on drug users in the area. Other members of the IJB are content with reassurances from officers that an impact assessment and risk mitigation plan will be put in place, and that the funding cut will result in savings to deliver efficiency and innovation in respect of other analogous services. You simply cannot accept that the funding cut is necessary or appropriate.

What can you do? You can ask for your dissent to be recorded in the minutes of the meeting, if you remain unhappy. Ultimately, however, if the decision is legal and was made in accordance with the IJB's standing orders, policies and procedures then it is legitimate, regardless of your opinion. You either need to accept that or consider whether you wish to remain as a member of the IJB.

You could be in breach of the Code if, outside the boardroom, you publicly criticise officers or make disrespectful comments about other members. This would include when you are posting on social media.

Case Studies

Confidentiality

You are a councillor representative on an IJB. You have been informed that the next meeting of the IJB will consider a proposal to close a significant number of care of the elderly beds within a hospital in your ward. This is to allow investment in alternative community-based models of care. You are concerned that people using care, their families and staff at the hospital in question have not been consulted on the proposed changes. You want to draw the matter to their attention so that their views are sought before a decision is taken. You consider the best way to do that would be to contact the local media to alert them to the proposal.
Can you do so?

No. If the proposal is not yet in the public domain and/or the intention is for it to remain confidential for the time-being, you could potentially be in breach of the Code's confidentiality provisions by divulging anything about the proposal without having first checked whether it should be kept private until considered. You should note that it may be that a plan to consult with those who could be directly affected by the proposal is to be discussed as part of the IJB's consideration of the matter.

REPORT TO:	East Lothian Integration Joint Board
MEETING DATE:	26 October 2023
BY:	Chief Officer
SUBJECT:	Provision of Adaptations funded by Private Sector Housing Grants

8

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1 PURPOSE

1.1 To update the IJB on actions underway to respond to a committed overspend in the East Lothian Private Sector Housing Grant (PSHG) budget. This is used to provide equipment and adaptations for people who live in privately owned or rented properties, in order to improve or maintain independent living and to avoid unnecessary hospital admissions or care packages.

2 RECOMMENDATIONS

The IJB is asked to:

2.1 Note the statutory functions applying to the provision of property adaptations and equipment to people with physical impairments, with the intention of assisting them in carrying out activities of daily living and maintaining independence.

2.2 Agree the mitigating actions by Community Occupational Therapy (ELC) and ELC Housing Services colleagues regarding adaptations/large equipment supply in owner occupied or privately rented properties.

3 BACKGROUND

3.1 East Lothian Council Housing Service manages an annual PSHG budget of £363,710 on behalf of the IJB. An additional budget of £329,890 for the Care & Repair service supports homeowners in the adaptation process.

3.2 In June 2023, East Lothian Rehabilitation Service (ELRS) received notification from ELC Housing colleagues of an anticipated overspend in the adaptations budget and were asked to review criteria used to determine eligibility for adaptations grant funding.

3.3 The adaptations budget is almost fully committed, with only £15k remaining and 26 homeowners' adaptations delayed until the new

financial year. Those cases that become critical will be considered in the first instance to ensure risks are mitigated where possible.

3.4 There are currently 245 people with a range of physical conditions waiting for an Occupational Therapy assessment. Of those waiting for assessment, 167 live in owner occupied properties or are privately renting.

3.5 The Occupational Therapy Service reviewed and updated the Occupational Therapy Practice Guide (Appendix 1) to ensure staff considered all resources available to clients seeking an adaptation. This approach aimed to deliver cost effectiveness, with more expensive solutions only contemplated once all funding avenues had been explored.

3.6 The Occupational Therapy service uses eligibility criteria set by Adult Social Work (Appendix 2). These have been further developed to reflect Occupational Therapy specific areas of function and help Senior Practitioner Occupational Therapists and Team Managers in ensuring consistency in approval processes. (Appendix 3)

3.7 The Occupational Therapy service continues to provide assessment, interventions and recommendations based on individual client need. Emergency criteria were not considered appropriate as this should not affect occupational therapy assessment principles.

3.8 The Occupational Therapy approach is supported and evidenced in the following documents:

- Home Adaptations Without Delay Planning Guide - RCOT
- Standards of conduct, performance and ethics (hcpc-uk.org).
- Assessment & provision - Equipment and adaptations: guidance on provision - gov.scot (www.gov.scot)
- Adult social care: independent review - gov.scot (www.gov.scot)

3.9 The Chronically Sick and Disabled Persons Act 1970, advises that Occupational therapists have a **duty to assess**, provide and make recommendations based on a person's, needs, wants or areas of importance to them. If these needs cannot be met through lower cost equipment, advice, rehabilitation, or self-purchase options then they may be eligible for a grant towards the adaptation. https://www.legislation.gov.uk/ukpga/1970/44/section/2.

3.10 Occupational Therapists are guided by government legislation and professional guidance from two governing bodies: the Royal College of Occupational Therapists (RCOT) and the Health and Care Professions Council (HCPC).

3.11 The RCOT Professional Standards for Occupational Therapy Practice, Conduct and Ethics state that: *We should ensure that all reasonable steps are taken to ensure the health, safety and welfare of any person involved in any activity for which you are responsible.*

3.12 All Occupational Therapists must meet HCPCs (Health & Care Professions Council) Standards of conduct, performance and ethics | (hcpc-uk.org). Some of these refer to assessment of needs of

individuals, covering: *Promote and protect the interests of service users and carers; Manage risk; Report concerns about safety and follow up any concerns.*

3.13 Where an Occupational Therapist has made recommendations for equipment, adaptations or other relevant service provision and there remains a risk to the persons health or wellbeing, they have an absolute duty to escalate these concerns to the relevant service provider.

3.14 Until the budgetary and demand pressures became apparent, the Occupational Therapy Service has not had oversight of the PSHG budget and have not contributed to the planning and management of these pressures. The Service is committed to continuing involvement in supporting Housing with effective clinical decision making and prioritisation of referrals where appropriate.

3.15 To address the anticipated PSHG overspend in this financial year, an Adaptations Panel was established to work collaboratively in agreeing prioritisation of cases requiring works. This will enable a focus on people living with impairments which affect their ability to manage tasks safely or independently within their own homes.

3.16 Where feasible, occupational therapy staff will regularly review people waiting for a decision on an adaptation. This will assist managers in highlighting cases to the Adaptations Panel where client risk has increased.

3.17 Monthly meetings will be held between Housing and Occupational Therapy to present critical cases where occupational therapists have assessed an increased risk of harm or injury to an individual if they do not receive an adaptation or equipment.

4 ENGAGEMENT

4.1 There have been ongoing discussions with the HSCP, Housing and the Care & Repair service with regard to the funding challenges for PSHG.

4.2 Housing has presented a paper to the ELC Executive Management Team (EMT) noting the financial implications and concerns regarding risks to delivery of statutory duties.

5 POLICY IMPLICATIONS

5.1 Provision of adaptations to property is a theme that cuts across the Strategic Delivery Priorities of the IJB Strategic Plan 2022-2025, including:

- Planning for an ageing population.
- Improving the management of long-term conditions.
- Meeting housing need.

6 INTEGRATED IMPACT ASSESSMENT

6.1 The subject of this report has not been subjected to an impact assessment. However, it should be acknowledged that provision of adaptations to a person's environment to enable them to be as independent as possible with daily living tasks or in being supported by formal and informal carers. Non-provision of a necessary adaptation can also have a significant impact on physical and mental wellbeing and potentially prevents the individual from being part of their community.

7 DIRECTIONS

7.1 Further discussion is needed on whether a Direction is required for adaptations provision.

8 RESOURCE IMPLICATIONS

8.1 The adaptations budget is almost fully committed to financial year end, with only £15k remaining unspent. Further detail is available in the ELC Members Library Report of 31 August 2023.

9 BACKGROUND PAPERS

9.1 Hyperlinks are provided in the text above to papers and legislation.

Appendices attached:

- Role & Remit of Adaptations Panel.
- Private Sector Housing Grant & Requests for Equipment and Adaptations.
- Occupational Therapy Practice Guide September 2023.
- Community Occupational Therapy Eligibility Criteria September 2023.
- East Lothian Councils Criteria for Service Users.

AUTHORS' NAME	Morven McLelland	Kirstie White
DESIGNATION	Team Manager, Occupational Therapy	Team Manager, Occupational Therapy
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DATE	18 October 2023	

Appendix 1

Committee name:	**Equipment & Adaptations (Private Sector Housing Grants)**
Chairperson:	Lesley Berry – General Manager & Chief AHP, East Lothian Rehabilitation Service
Alternate:	Kirstie White or Morven McLelland
Remit:	• Solely for owner occupied and privately rent accommodation • Assurance and governance of clinical decision making • Prioritisation of cases • Escalation process to IJB
Role:	• Multidisciplinary and collaborative approach • Ensuring equity across decisions made
Reports to:	• Fiona Wilson • Monica Patterson • IJB
Members:	Lesley Berry – *General Manager, East Lothian Rehab Service & AHP Lead, East Lothian* Morven McLelland – *Team Manager, Occupational Therapy* Kirstie White – *Team Manager, Occupational Therapy* Wendy McGuire – *Head of Housing* Stephanie Irvine – *Team Manager* Rebecca Pringle – *Team Manager for Housing Strategy in ELC* Louise Dickson – *MSK Clinical Lead & Physiotherapy Professional Lead* Gerry McFeely – *Professional Lead Occupational Therapy*
Also inform of progress/ request reports from:	• EMT • Cabinet
Role of members	• Attend meetings regularly or send named alternate • Report back to relevant area about outcome of meetings • Devise suitable group action plan and deliver actions in timely manner • Case discussions • Consensus of prioritisation
Frequency:	Once a month
Circulations of minutes:	Members of the panel
Directives:	NHS Healthcare Improvement Scotland Standards Adaptations without delay HCPC directions Independent review of adult social care Public bodies (joint working Scotland act) 2014 Social Work Scotland Act 1968 Chronically Sick and Disabled Persons Act 1970 Housing Scotland Act 2006 & 1987 Rehabilitation Framework Health & Social Care Standards: My Support, My Life National Carers Strategy IJB Strategic Plan 22-25
Supporting documentation:	Practice Guidance Eligibility Criteria Occupational Therapy Recommendation Process
Review Date	March 2024

Private Home Sector Grant (PHSG) Requests for Maintainable Equipment & Major Adaptations

Appendix 2

August 2023.

Background

Due to current budget constraints with the PSHG, the Occupational Therapy service managers were asked to develop criteria for Housing to work with in order to help prioritise clients waiting for maintainable equipment and major adaptations.

The Occupational Therapy service will continue to carry out assessments and recommendations for equipment and adaptations and pass these recommendations onto the relevant housing provider. These will be approved in line with current local and national legislation and in addition in line with our professional and governing body of the Royal College of Occupational Therapists (RCOT) and Health & Care Professions Council guidance and recommendations.

In order to support requests for maintainable equipment and adaptations will all be prioritised on a weekly basis. Occupational Therapy Team managers will be responsible for this task and will use East Lothian Councils current eligibility criteria. They will be rated Critical/Substantial/Moderate/Low Need. There is further guidance for Occupational Therapists and Managers to explore in more detail threshold levels. This can be found in the Occupational Therapy guidance for eligibility criteria.

Criteria Terms/Definitions

East Lothian Councils eligibility criteria sets out the level of risk for each definition as follows. (Eligibility Criteria | East Lothian Council)

Critical: The risk of harm/ danger to a person or major risks to independence

Substantial: The risk of significant impairment to the health and well-being of a person or significant risk to independence

Moderate: The risk of some impairment to the health and well-being of a person or some risk to independence

Low: Promoting a persons' quality of life or low risk to independence.

Specifically in relation to Occupational Therapy provision of equipment and adaptations the threshold for service provision is established at moderate.

Section 2: Needs Relating to Your Personal Care / Domestic Routines / Home Environment

Critical	• You are unable to do vital or most aspects of your personal care causing major and immediate harm or danger to yourself or others or major and immediate risks to your independence and you need social care support. • You are unable to manage vital or most aspects of your domestic routines causing major and immediate harm or danger to yourself or others or major and immediate risks to your independence and you need social care support. • You have an extensive / complete loss of choice and control over vital aspects of your home environment causing major and immediate harm or danger to yourself or others or major and immediate risks to your independence and you need social care support.
Substantial	• You are unable to do many aspects of your personal care causing significant risk of danger or harm to yourself or others or significant risks to your independence either now or in the near future and you need social care support. • You are unable to manage many aspects of your domestic routines causing significant risk of harm or danger to yourself or others or significant risks to your independence either now or in the near future and you need social care support. • You have substantial loss of choice and control managing your home environment causing a significant risk of harm or danger to yourself or others or a significant risk to your independence and you need social care support.
Threshold for Services	
Moderate	• You are unable to do some aspects of your personal care indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your domestic routines indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your home environment indicating some risk to your independence either now or in the foreseeable future.
Low	• You have difficulty with one or two aspects of your personal care, domestic routines and / or home environment indicating little risk to your independence.

Please refer to the Occupational Therapy Practice Guide for detailed information on provision of equipment and adaptations. This provides detailed and up-to-date guidance on what we are able to provide and where people may need to source additional 'private' funding for more high-end non-essential equipment/adaptations.

Palliative Care Requests for Equipment & Adaptations

In cases where clients' either have a DS1500 in place or where there is a life expectancy of less than 6-months, the service may only be able to offer a short-term solution e.g., essential equipment such as commode/ chemical toilet or medium-term options including shower/ toilet cubicle. It must be realistic to achieve within timescales and not cause significant upheaval and distress to the client and family receiving equipment.

There are several situations where a client may have a life limiting condition (may not be palliative at time of request for assistance) such as MND (Motor Neurone Disease). A comprehensive assessment will be provided, however temporary equipment/adaptations may be recommended in these instances as opposed to longer term adaptations due to timescales currently taken for provision.

Appendix 2

ELIGIBILITY CRITERIA CHECKLIST
Community Care Services

Name: _____ Date of Birth: /____/

This form must only be completed following an assessment or review to determine if a person has social care needs that are eligible for services arranged or provided by East Lothian Council

Section 1: Needs Relating to Your Physical and Mental Health

Critical	• You have major health problems which cause immediate life-threatening harm or danger to yourself or others and need social care support. • Serious abuse or neglect has occurred or is strongly suspected, and you need protective intervention by Social Work (includes financial abuse and discrimination).
Substantial	• You have significant health problems which cause significant risks of harm or danger to yourself or others either now or in the near future and need social care support. • Abuse or neglect has occurred or is strongly suspected in the near future, and you need social care support (includes financial abuse and discrimination).
Threshold for Services	
Moderate	• You have some health problems indicating some risks to your independence and / or intermittent distress either now or in the foreseeable future.
Low	• You have a few health problems indicating low risks to your independence.

Note: Mental Health within Critical and Substantial: includes severe enduring mental illness / Regular episodes of severe mental illness, acute mental breakdown, life threatening or serious chronic substance misuse / neglect.

Section 2: Needs Relating to Your Personal Care / Domestic Routines / Home Environment

Critical	• You are unable to do vital or most aspects of your personal care causing major and immediate harm or danger to yourself or others or major and immediate risks to your independence and you need social care support. • You are unable to manage vital or most aspects of your domestic routines causing major and immediate harm or danger to yourself or others or major and immediate risks to your independence and you need social care support. • You have an extensive / complete loss of choice and control over vital aspects of your home environment causing major and immediate harm or danger to yourself or others or major and immediate risks to your independence and you need social care support.
Substantial	• You are unable to do many aspects of your personal care causing significant risk of danger or harm to yourself or others or significant risks to your independence either now or in the near future and you need social care support. • You are unable to manage many aspects of your domestic routines causing significant risk of harm or danger to yourself or others or significant risks to your independence either now or in the near future and you need social care support. • You have substantial loss of choice and control managing your home environment causing a significant risk of harm or danger to yourself or others or a significant risk to your independence and you need social care support.
Threshold for Services	
Moderate	• You are unable to do some aspects of your personal care indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your domestic routines indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your home environment indicating some risk to your independence either now or in the foreseeable future.
Low	• You have difficulty with one or two aspects of your personal care, domestic routines and / or home environment indicating little risk to your independence.

Section 3: Needs Relating to Your Family and Social Responsibilities

Critical	• You are unable to sustain your involvement in vital or most aspects of work / education /learning causing a major and immediate loss of your independence and you need social care assistance. • You are unable to sustain your involvement in vital or most aspects of family / social roles and responsibilities and social contact causing major distress and / or immediate loss of your independence and you need social care support.
Substantial	• You are unable to sustain your involvement in many aspects of work / education / learning causing a significant risk to your independence either now or in the near future and you need social care assistance. • You are unable to sustain your involvement in many aspects of your family / social roles and responsibilities and social contact causing significant distress and / or risk to your independence either now or in the near future and you need social care support.
Threshold for Services	
Moderate	• You are unable to manage some aspects of your involvement in work / learning / education indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your family / social roles and responsibilities and social contact indicating some risk to your independence either now or in the foreseeable future.
Low	• You have difficulty undertaking one or two aspects of your work / learning / education / family and / or social networks indicating little risk to your independence.

Section 4: Carers

Critical	• Your carer has major physical / mental health difficulties due to the impact of their role as a carer causing immediate life-threatening harm or danger to themselves or others and they need social care support. • There is a complete breakdown in the relationship between you and your carer and your carer is unable to continue caring or has difficulty sustaining vital or most aspects of their caring role. • Your carer is unable to manage vital or most aspects of their caring / family / work / domestic / social roles and responsibilities and needs social care support.

Substantial	• Your carer has significant physical / mental health difficulties due to the impact of their role as a carer causing significant risk of harm or danger to themselves or others either now or in the near future and they need social care support. • There is a significant risk of breakdown in the relationship between you and your carer and your carer is unable to sustain many aspects of their caring role either now or in the near future. • Your carer is unable to manage many aspects of their caring / family / work / domestic / social roles and responsibilities either now or in the near future and needs social care support.
Threshold for Services	
Moderate	• Your carer is unable to manage some aspects of their caring / family / domestic / social roles either now or in the foreseeable future.
Low	• Your carer has difficulty undertaking one or two aspects of their caring / domestic role.

Appendix 3

OCCUPATIONAL THERAPY PRACTICE GUIDE

September 2023

Contents *Page No*

Introduction

This document has been prepared with the aim of providing guidelines for the provision of several types of equipment, adaptations, and alterations in the homes of children and adults with disabilities. The document refers to the Scottish Government Eligibility Criteria as it applies to Occupational Therapy and East Lothian Rehabilitation Service

Should anyone wish to see a section of the document it is essential that page 2 (Description of Service, Conditions, Criteria) is also given.

Description of the Service

East Lothian Health & Social Care Partnership and Housing provides people with physical impairments with equipment and/or adaptations to use in their own homes to help them be as independent as possible in activities of daily living.

Disability (now known as Physical Impairment) is defined in the legislation as "a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities." (Disability Discrimination Act 1996).

Criteria for Occupational Therapy

The criteria for this service is that the person is:

- A person with a physical impairment (disabled person) as defined in the Disability Discrimination Act 1996. Any disabled person will be entitled to an Occupational Therapy Assessment. However, assessment will indicate whether the person meets the criteria for equipment and/or adaptation provision.

Specific Guidance on provision is noted below.

Specific Criteria can be found in additional guidance (Occupational Therapy Eligibility Criteria Guidance 2023)

Considerations for Service Provision

- The equipment and/or adaptation must be at the person's only or main residence as defined in the relevant Housing Acts

- The type of service provided will depend on the person's condition, level of need, and the technical suitability of the property and site.

- Where a property is unsuitable to be adapted (i.e., where multiple adaptations and maintainable equipment is required to make the property more suitable, or the cost is prohibitive), rehousing may be recommended.

- Where appropriate, the Landlord may offer suitable alternative accommodation instead of adapting the property

- Equipment and/or Adaptations will not be considered if the person has applied for or is considering moving house.

- A major adaptation will only be carried out on one house for a person and ELH&SCP or Housing will not contribute towards adapting a subsequent house. One exception to this would be where there is a substantive reason for moving house such as moving to retain employment. A second exception is where the council's contribution to the adaptation is the subject of a Minute of Agreement. Any exceptions noted above should be presented to the Joint Complex Cases Panel (JCCP) for consideration.

- Occupiers/owners of properties affected by the adaptation e.g., a ramp on a common pathway, must give their permission for the adaptation.

General Advice for Clients requiring an Adaptation

1. The planning of the adaptation should consider the client's current and long-term needs.

2. The timescale of a major adaptation is lengthy. The process should be fully explained to the client and advised of the indicative waiting times for completion of adaptations.

3. Generic property repairs are the responsibility of the property owner and cannot be undertaken by East Lothian Health & Social Care Partnership (ELH&SCP).

4. Adaptations and some large maintainable equipment, unless otherwise stated in the legal letters, become a part of the property and the responsibility for the maintenance and repair rests with the property owner.

5. It should be noted that a new tenant moving into a previously adapted house accepts the house as seen, i.e., ELH&SCP and Housing do not remove adaptations or reinstate the property (see legal letters).

6. There may be other work considered desirable by the client, which cannot be funded by the ELH&SCP. Advice and information will be offered on alternative funding for such work.

GUIDANCE NOTES FOR PRACTITIONERS

4. ACCESS

1.1 Paths
1.2 Paved areas
1.3 Rails on steps
1.4 Ramps
1.5 Shallow steps
1.6 Entryphone's
1.7 Door opening devices
1.8 Flashing Doorbells

1.1 Paths

Description - Any altering, relaying, or repositioning of an essential access path within the confines of the client's property.
The width of the access path should be no less than 900 mm (preferably 1000mm), with a safety edge where appropriate.

ELH&SCP will not provide a rail alongside an access path.
It is normally expected that a client can walk along a path using a walking aid. If after joint assessment with a physiotherapist the client is assessed as being at risk a rail can be provided at the discretion of the Senior Practitioner Occupational Therapist.

Criteria:

- Where a person is at risk of falls whilst using a path which is not fit for purpose and would not fall under a 'repair' requirement
- A suitable path for use of a wheelchair user (attendant or self-propelled) i.e., chipped path would not be suitable.

Factors To Consider

a) If the disabled person has prime responsibility for household chores and can use the washing line or rotary drier, consideration may be given to providing a suitable path to access these facilities. The existing surface must be adequate for an ambulant person to undertake the same chore that is considered hazardous for the disabled person.
b) It is the responsibility of the occupier to treat the path to remove ice.
c) If a path requires maintenance or re-laying for routine use, then this is seen as the responsibility of the property owner.

1.2 Paved Areas

Description - A level area either with slabs or a suitable safe material.

Criteria:

- Where a person is at risk of falls whilst using a path which is not fit for purpose and would not fall under a 'repair' requirement
- A suitable path for use of a wheelchair user (attendant or self-propelled) i.e., chipped path would not be suitable.

Factors To Consider

a. A paved area under a washing line may be provided where it is needed to assist a person to be functionally independent.
b. A play area for a child would be paved to assist with mobility. The normal area to be paved will be to the maximum of 15 square meters.

1.3 Rails on steps to Main Access Points of Property

Description - Metal or wooden handrail by steps or stairs.

Criteria

- Where a client is unable to manage 2 or 3 steps to their main door.

Factors To Consider

a) It is the responsibility of the house owner to provide, repair or replace one rail:
    - for an outside stair which rises more than 600mm above the ground.
    - for an internal staircase. (Building Regulations).
b) A second handrail will only be provided if one rail is insufficient for the need. e.g., due to a hemiplegia where the person is only able to use one side of their body.
c) If a second rail is considered it is necessary to check that the steps are of sufficient width. Second rails can cause obstruction especially in narrow areas.
d) It is the responsibility of the occupier to treat the path to remove ice.

1.4 Ramps

Description - There are three types of ramps: -

- Portable – that is, easily removed for short-term, intermittent, or urgent use.
- Temporary Modular – fixed reusable ramp.
- Permanent – considered for long-term use where the property is wheelchair accessible.

Criteria -

- Where you can only gain access to the house using a wheelchair, we may provide a ramped access if it is practical and feasible to do so.
- ELH&SCP only provide a ramp at one entrance to a property.
- A permanent ramp will only be considered if the house is wheelchair accessible throughout e.g., bungalow
- If the principal areas of the house are not wheelchair accessible, we will only install portable or temporary modular ramping.
- If you can negotiate steps to gain access to your property, a ramp will not be provided. This also applies if you are only able to do so with the aid of a helper.
- ELH&SCP will only consider providing ramped access if you meet the criteria for provision of an NHS (National Health Service) wheelchair.

Factors To Consider

- Ramp Gradient – removable and permanent ramps have a preferred gradient of 1:20, although no steeper than 1:12.
- Portable ramp provision is subject to a risk assessment as it may be difficult to achieve an ideal gradient.
- All ramps will be installed subject to current building regulations.
- Ramp Width for a for a domestic dwelling must be a minimum of 1200mm. (Housing for Varying Needs Standards (HFVN))
- Ramp Handrails - Building Regulations require that handrails be provided to ramps with a change of level over 600mm, except where the side is against a stable structure. The recommendations would be that: -
    - Any ramp with a total rise of more than 600 mm shall be provided with a handrail:
- on each side if the ramp is 1000mm or wider;
- on at least one side in any other case; and
    - Any such rail shall
- be designed to afford adequate means of support to persons using the ramp;
- be continuous for the length of the ramp;
- be securely fixed at a height not less than 840mm nor more than 1000mm (measured vertically from the top of the surface of the ramp);
- where requirement dictates be terminated by a scroll or other suitable means;
- A platform at the entrance door of 1500 x 1500mm is essential and the same space available at the bottom of the ramp.
- When a ramp is over 5m long, planning permission and building warrants are required.

- A maximum length of 10 meters between landings is required of gradients 1:20 – 1:15 and 5 meters with slopes steeper than 1:15. Housing for Varying Needs (HFVN)
- It is the house occupier's responsibility to treat the ramp to remove ice.

N.B For further information consult Housing for Varying Needs (1998)

1.5 Graded Steps

Description – Steps can be adjusted (height and depth) to improve access with a fixed removable step (permanent alterations have not been provided since October 2022).

Criteria

- Unable to negotiate current steps with or without a walking aid, does meet criteria for a ramp.

Factors To Consider

a) If a client uses a walking frame e.g., a Zimmer, it is a necessary to ensure that the depth of the new step is sufficient to take the frame and feet of client safely.
b) The client's ability to step up must be measured to ensure that the height of the steps fall within their capability.
c) A fixed removable step should be considered when a permanent alteration is inappropriate due to prognosis or environmental constraints.

1.6 Entryphone

Description – An intercom to allow a client to talk to the person at the door and let them in by activating a door lock release device.

Criteria -

- The client cannot reach the door, or the effort is detrimental to his/her health and the client lives alone or is left alone for prolonged periods.

Factors to consider

a) ELH&SCP will not provide an entry phone on the grounds of security for clients with a visual impairment. Advice or signposting will be given on Intercom systems.
b) ELH&SCP may be able to provide a handset which may be either free-standing or wall mounted.
c) An entry phone may form part of Environmental Control System.
d) Keypad entry system or Key Safe boxes should be considered, which permits access to those who know the coded system.

1.7 Door Opening Devices

Description - A radio-controlled device which, when activated, unlocks, and opens a door, with time delayed closing. Can be installed on external or internal door.

Criteria -

- The client is unable to physically open or close a conventional door but can operate this device and the client lives alone or is left alone for prolonged periods.

Factors to Consider

Depending on the condition and any additional needs the person may have, consideration of referral to Environmental Controls Team may be more appropriate.

1.8 Flashing Doorbells

Provided for people with hearing loss. Equipment assessed by Deaf Action and provided by ELH&SCP. Fitting of equipment arranged through Deaf Action.

2. BATHROOM & TOILET ADAPTATIONS

2.1 Bathroom and/ or toilet
2.2 Overbath shower
2.3 Wet floor shower/ level access shower tray
2.4 Additional toilet
2.5 Combined shower/ toilet unit e.g., converted WC room or a shower/loo

2.1 Bathroom And/or Toilet

Description - Provision of a suitable washing and toileting facility.

Criteria:

- The existing facilities are not accessible and cannot be reasonably adapted to make them accessible and/or suitable for the disabled person.
- Access to the existing toilet cannot be provided and alternatives, e.g., a commode or chemical toilet, are assessed as being inappropriate
- Where there is sufficient space elsewhere no consideration will be given to providing an extension.

Considerations:

The decision will consider medical condition and longer-term outcomes for the individual.

SHOWERS

Description –The provision and installation of a thermostatic shower that meets British Standards Institution recommendations.
The options are:

- Overbath Shower
- Wet Floor Shower Area
- Level access shower tray.
- Combined shower/WC unit e.g., converted WC room or a Chiltern shower/loo.

For more information see each of the following sections

Criteria –

- If the person has had a period of rehabilitation and is no longer able to use bathing equipment safely independently or with assistance, ELH&SCP would consider one of the above options.
- There is a medical or behavioural risk associated with having a bath e.g., severe autism
- ELH&SCP will only remove the bath if the person is unable get in and out safely with equipment or help.

2.2 Overbath (OB) Shower

Description - The provision and installation of a thermostatically controlled overbath (OB) shower that meets British Standard Institution recommendations.

Criteria -

- Ability to transfer in/out of the bath with or without equipment to use the OB Shower.
- The client will have the ability to use this method for the foreseeable future.
- Submersion in water is not advised.

Factors To Consider

a) All showers should be located at an appropriate height for the client's ability, position, and, if necessary, carers use.
b) The showerhead should be detachable and on an adjustable slide to allow height variation. This adjustable slide should be set at a height appropriate to the client's needs.
c) Are controls specific to client's disability required.
d) The removal of the bath would not increase the client's independence or relieve the carer of difficulties.
e) Where the installation needs to be achieved quicker and with as little upheaval as possible.
f) Other family members' physical need for a bath.

g) People with an uncontrolled seizure disorder are advised to use the OB shower seated on the bottom of the bath.

NB: Colostomy/Ileostomy/Urostomy. People with these should be able to use the bath in the normal way. If, however, the person has another condition which necessitates the use of a shower this may be considered.

2.3 Wet Floor Shower Area/ Level Access Shower

Description – a barrier free shower area where the floor has a slight gradient leading to drainage to enable showering independently or assisted by a person using a wheeled shower chair.

Criteria -

- All bath equipment has been tried and proved unsuccessful.
- The client cannot access the existing shower cubicle.
- A shower adaptation will meet the long-term need of the client

Factors To Consider

a) All showers should be located at an appropriate height for the client's ability, position and, if necessary, carers use.
b) Need for appropriate screen/curtain to contain water and enable carer to assist if required
c) The gradient to the drain should be gently sloping in order to ensure the stability of any floor standing equipment, wheeled shower chair etc.
d) There should be adequate sealing round edges e.g., toilet pedestal base.
e) This option allows optimum circulation space in a limited environment.
f) A level access shower tray may need to be considered where the property is not suitable for a wet floor shower area.

2.4 Additional Toilet

Criteria –

- The client is assessed as being unable to reach and/or use the existing toilet and it is not possible or practical to provide access.
- Alternative solutions are assessed as being inappropriate e.g., bottle, commode, or chemical toilet. A stairlift could be considered as a more cost-effective solution.
- There is a permanent medical condition causing frequent and urgent bowel movements.

2.5 Wash Dry Toilet

Definition – a toilet with wash/dry facility, e.g., Closomat or Bio bidet

Criteria: -

- The client is assessed as being unable to maintain proper hygiene after toileting and alternatives have been assessed as inappropriate.
- The client has tried a wash/dry toilet and finds it an acceptable solution.
- The provision would give the client independence in toileting and may reduce care needs for personal hygiene tasks.

Factors to consider

a) A plinth may be required to raise toilet to the appropriate height, especially if used with a shower chair. Due consideration should be given to other family members.
b) Where possible it is advisable for these wash/dry toilets to be trialled in case clients are unable to tolerate them.
c) Type of flush mechanism e.g., back bar, foot pedal.
d) Weight limit of the client will inform the type of wash/ dry toilet being considered
e) Check manufacturers recommendations for further information

3 SEATING (CHILDREN AND ADULTS)

Description – Specialist adjustable chairs provided on loan by the department.

Criteria -

- The client requires postural management to reduce risk of contractures and further deterioration of posture.
- To allow improved nutritional intake in a more upright position.
- To allow good positioning for socialising and stimulation.

4. HOISTS, STAIRLIFTS & STAIRCLIMBERS

4.1 Mobile hoists
4.2 Overhead hoists
4.3 Stairlifts
4.4 Stairclimbers

4.1 Mobile Hoists

Description – mobile hoists are available on request via Community Equipment Loan Store (CELS).

Criteria:

- Client is unable to transfer independently with support from a carer
- Other equipment e.g., Sara Steady, Patient turner or Standaid hoist are not appropriate
- A suitable risk assessment has been completed by an appropriately qualified/ accredited clinician

Factors to consider

a. Suitable space for circulation of the mobile hoist
b. 2. Clearance for legs underneath chair/bed and wide enough to accommodate toilets etc.
c. 3. Suitable staff trained to use the equipment
d. 4. OT must complete a risk assessment and safer handling plan and pas to relevant care provider to support the care at home.
e. 5. All Moving and handling tasks should be placed on Statutory review list (annual review).

4.2 Fixed Overhead Hoists

Description - Electric hoist that is suspended from a length of overhead track fitted in one of these ways.

- Ceiling fixed
- Full coverage (e.g., H or X & Y systems)
- Wall mounted
- Floor fixed i.e., Gantry

Criteria -

- Mobile hoists have been considered and tried and are inappropriate due to ability of carer or lack of space.
- Where single handed care could be provided (with appropriate training) by a formal or informal carer
- The person has severely limited function making transfers inadvisable without mechanical assistance.
- The provision will increase the clients' independence in transfers.

Please note, there are occasions where a client may be able to self-transfer using a ceiling track hoist without assistance. If a client has been assessed as being able to self-transfer using a ceiling track hoist, this MUST have a detailed risk assessment completed and uploaded to Mosaic.

Factors To Consider

a) The provision is dependent on structural feasibility and an asbestos survey may be required.

b) Safe use of hoist requires correct positioning of the client and sling and adequate fastening of the sling. Where the client lives alone or will use the hoist alone the presence of symptoms impairing the judgement needed for safe use of the hoist may preclude the supply of the hoist.

c) More than one track hoist may need to be installed.

d) In some instances, the track may run between rooms.

e) Safe use of hoist requires training in correct positioning of client and correct sling; adequate fastening of sling; appropriate sequencing of ascent/descent/traverse controls etc.

f) OT must complete a risk assessment and safer handling plan and pas to relevant care provider to support the care at home.

g) All Moving and handling tasks should be placed on Statutory review list (annual review).

4.3 Stairlifts

Description – A straight or curved piece of track fixed to the stair with a suitable chair which allows a person to ascend/descend the stairs to access essential facilities in the persons property.

Criteria -

- The client cannot negotiate stairs or is unsafe doing so, even with additional stair rails.
- The client does not have access to internal essential facilities of bathroom and bedroom, nor can accessible facilities be created.
- It is medically contra-indicated for the client to negotiate stairs.

N.B A stairlift would not be installed on a common or shared staircase.

Factors To Consider

a) The persons abilities - to sit down, to transfer to a seat, to manage the controls, whether they need a specific height of seat, specialised seat, or harness and whether their abilities will change in the near future.
b) Client has a cognitive impairment affecting ability to safely use controls and/ or learn and follow instruction
c) Spatial orientation problems are present.
d) Severe epilepsy
e) Anxiety factor unresolved by trial use.
f) The clients weight

g) Progressive neurological conditions where ability to transfer will be affected e.g., if the client requires to use a Patient turner or hoist
h) Turning space available to the top and bottom of the stairs
i) Whether track would require to cross a door
j) The supplier must ensure that the lift complies with current building regulations.
k) If HIG (Home Improvement Grant) funded the owner is required to LOLER check the stairlift especially if paid care staff are required to assist client with transfers on/off.
l) Other people in the household - others who will be using the stair and ensuring safe access for them and the needs of other people in the household.
m) If there is space for a bedroom downstairs but no toilet/bathing facilities it may be more cost effective to provide a ground floor toilet/shower.
n) All Stairlifts provided/funded by ELC (East Lothian Council) will have an annual service and LOLER check as standard.

N. B A stairlift can be operated by a carer if the client is unable to do so themselves.

4.4 Stair climber

Description – Carer operated mobile transporter to carry wheelchair and passenger up and down stairs. These are provided by CELS.

Criteria -

- The carers must be willing to undertake training and be competent in the use of the equipment.
- The client cannot negotiate stairs or has been medically advised not to.
- The client cannot get to internal essential facilities, as access cannot be created.

Factors To Consider

a) An assessment visit has been completed by the relevant trainer (organised through the Community Equipment Loan Service)
b) The stair is wide enough for a Stair climber, particularly where bends must be negotiated.
c) The suitability of the wheelchair and whether it can fit onto a Stair climber safely and securely.
d) Client and carers must receive training in the use of the Stair climber by the supplier.

5 GENERAL ALTERATIONS TO LIVING SPACES

5.3 Bedrooms
5.4 Kitchens

5.1 Bedrooms

Description - Provision of an accessible bedroom.

Criteria:

- The existing facilities are not accessible and/or suitable for the disabled person.
- Where there is sufficient space elsewhere no consideration will be given to providing an extension.
- It is not possible to provide stairlift access to the existing bedroom.
- There is only one public room on the ground floor and there is more than one person in the household.

Factors To Consider

a) Rehousing to suitable accommodation should be considered.
b) The decision will take into account prognosis.
c) Alterations or extensions to living space may only fulfil the essential requirements of the disabled person.
d) Where there is a downstairs bathroom, and a sitting/dining room, consideration should be given to partition off the dinette to form a bedroom

N.B. ELH&SCP do provide accessible bedrooms in owner occupied properties but may contribute to provision of essential bathroom facilities should the client wish to progress this type of adaptation privately. East Lothian Council Housing may consider an adaptation of this type in their housing stock if other options for re-housing have been exhausted. Any recommendation for an accessible bedroom must therefore be presented to JCCP for consideration.

5.2 Kitchens

Description - The redesign or reorganisation of kitchen facilities.

Criteria -

- The person with the disability is the predominant user of the kitchen and is responsible for the preparation and cooking of food for self-and/or family.

Factors To Consider

a) The decision will take into account medical condition and longer-term outcomes for the individual.
b) Alterations or extensions to living space will only fulfil the essential requirements of the person with disabilities and will not include the provision of replacement white goods.
c) The adaptation will consider the use of the kitchen by other household members. i.e. The extent of a kitchen adaptation will depend on whether the person with the disability is the predominant user. Where minimum use only is envisaged, the provision might only be access and a single accessible work surface.

6. HOME SAFETY

6.1 Window/ door locks
6.2 Smoke alarms
6.3 Gas isolation
6.4 Baby alarm/ intercom communication
6.5 Monitoring equipment
6.6 Glazing
6.7 Padded walls
6.8 Fencing
6.9 Gates (internal and external)

6.1 Locks on Internal Doors and Windows

ELH&SCP may provide these if required for the safety of a child or adult. However, a fire safety risk assessment should be completed by the Scottish Fire & Rescue Service and discussion with the landlord is required.

6.2 Smoke Alarms

It is the homeowner or landlords' responsibility to ensure linked smoke detection is in place within their property in line with current legislation. ELH&SCP may provide specialist smoke detection in properties for people with a hearing or visual disability following an assessment from sensory disability services.

6.3 Gas Supply – Alarms or Isolating Switches

Carbon monoxide monitors should be available when gas central heating is in place. They can also be considered as part of a Telecare/ TEC assessment. ELH&SCP can arrange gas isolation if risk is identified with a client accessing gas appliances e.g., if the client has a cognitive deficit.

6.4 Baby Alarms/Intercom Communication

These are no longer provided by CELS. However, there are now Technology Enabled Care (TEC) options available for people to self-purchase including use of Google Home, Alexa etc. These options are often requested where there needs to be communication between two rooms in a house.

These are not provided for monitoring small children, when the use of a baby alarm is considered as a normal responsibility of the parents.

6.5 Monitoring Equipment

Will be considered when safety is an issue and to provide carer support. TEC options may also be privately purchased by a client or carer to support someones' needs at home. e.g., Alexa, Google Home etc.

6.6 Glazing

Toughened glass can be provided where a person with challenging behaviours may be liable to smash windows and/or glass doors and cause injury to self or others.

6.7 Padded Walls

Padding to walls can be provided where a person with challenging behaviours' may be liable to punch walls and cause injury to self or others.

6.8 Fencing

Description – A fenced area in a domestic garden providing a safe space for children to play. Fencing provided will meet the following standard:

- Wire mesh to a maximum of 1.8m height or wood with upright slats to a maximum of 1.8m height.
- The area to be fenced will depend on the layout of the garden but should be no greater than 40 square meters.

Criteria -

- The existing recreation space does not provide safety and security for the person with a disability; and/or
- The carer has a disability which prevents safe supervision of the person they care for.

Factors To Consider

- Communal access

Fences will NOT be considered in the following situations:

a. To keep out other children and dogs.
b. To solve disputes between neighbours
c. Only one secure area will be provided.

6.9 Gates (Internal & External)

Description - This will be a wood or metal barrier to make an external area secure.

Criteria -

- A gate would be fitted to complete a safe area that would prevent a vulnerable person from wandering into a hazardous area.

Description - A secure fixed barrier to make an internal area secure.

Criteria -

- A gate may be fitted where a person needs to cross the stair head and is in danger of falling.

Factors To Consider

a) A gate would not be fitted to resolve problems of vandalism or trespass.
b) A risk assessment must be carried out before proceeding.

7. TRANSPORT, DRIVEWAYS, DROPPED KERBS

7.1 Adaptations to cars
7.2 Special car seats & harnesses
7.3 Parking signs
7.4 Disabled parking bays
7.5 Driveways for cars
7.6 Dropped Kerb for a car
7.7 Sheds for outdoor power wheelchairs

7.1 Adaptations to Cars

ELH&SCP do not fund adaptations to cars for either a disabled driver or passenger as the Personal Independence Payment (mobility component) should be used for this purpose.

7.2 Special Car Seats and Harnesses for Children

ELH&SCP is not responsible for supplying and fitting such equipment when it is normally required by law for a child of that age, apart from exceptional circumstances.

Criteria -

- A child cannot be held safely and securely by any of the above equipment.

Factors to consider

Please refer to the guidance leaflet

7.3 Parking Signs

Description - Metal sign with the legend “Disabled Person - Please leave parking space” which is attached to the client’s boundary fence or similar.

These signs can be privately purchased from DIY stores and therefore are no longer funded by ELH&SCP

N.B. These signs have no legal standing but rather they exert a moral pressure on other drivers to leave a parking space.

7.4 Disabled Parking Bays

Description – a bay specifically marked for use by a person owning a blue badge.

An Occupational Therapist can request the Roads service mark the road with a disabled bay for a person. However, the person must be advised that it is not possible to allocate a parking space for an individual disabled driver on a public road in East Lothian. Therefore, if there is a parking bay directly outside a persons' house, anyone else with a blue badge may use this space.

7.5 Driveways for Cars

Description - A suitably solid surface (concrete, slabs, tarmac, or chips as appropriate) within the boundary of the client's home which allows access to their car.

N.B Local regulations for construction of driveways needs to be taken into account.

Criteria -

- The driver is a Blue Badge holder who is unable to walk or propel a wheelchair to the car parked at the kerb.
- The passenger is a Blue Badge holder, and the driver is unable to push a wheelchair from the kerb.

Factors To Consider

a) Although a client/carer may meet the above criteria, it may not be possible for the provision to be made due to local planning or traffic considerations.
b) Passengers will not normally qualify as it is not unreasonable to expect that an able-bodied driver should 'double park' if necessary to set down the disabled passenger and remove the vehicle afterwards. Although this may entail short-term obstruction of the highway, as it is not either 'unnecessary' or 'wilful' it is unlikely to be considered an offence.
c) Exceptions may be made where the passenger requires constant attendance or, where the driver is of advanced age or frailty and must lift equipment, which could put themselves at some risk if doing so in busy streets etc. wheelchair etc.
d) Consideration will not be given to provision of a run-in to prevent vandalism

N.B. Consideration will not be given to provision of a driveway where the person has difficulty finding a suitable parking space.

7.6 Dropped Kerb for a Car

Description - A section of kerb lowered to provide access for a car into a driveway

Criteria -

- If a driveway is formed the kerb will require to be dropped. A client who meets the criteria for a driveway would therefore be provided with a dropped kerb as part of the adaptation.

N.B. If a client already has a driveway but the kerb is not dropped, the client requires to meet the criteria for a driveway before ELH&SCP will authorise the dropped kerb.

Factors To Consider

a) The specification for the dropped kerb and permission to drop the kerb must be obtained from the Roads Department who will subsequently inspect the work.
b) If a client is arranging a driveway themselves, they require to be informed that they will need to arrange for the kerb to be dropped. They require to notify Roads Department of their intention. Roads will then supply specification permission and will inspect the kerb drop when complete.

7.7 Sheds/Accommodation for Electric Outdoor Chairs

The maintenance and shelter of privately obtained outdoor power chairs, scooters or vehicles is the responsibility of the owner.

ELH&SCP do not provide paved areas, dropped kerbs, driveways, charging facilities or shelter/ storage for any electrical/battery operated vehicles.

8. Previous Criteria (now removed as no longer pertinent) - *information held in case of exceptional circumstances.*

8.1 Heating

ELH&SCP do not provide alternative forms of heating, unless in exceptional circumstances. Staff will advise or assist the client in making applications for funds where appropriate.

Criteria -

- Client is physically unable to manage their existing source of heating independently without risk.
- All occupants of the house meet the criteria.

Factors to consider

a) Where a client has difficulty turning on/off a gas fire it may be possible to fit an extended handle. This would be done by the Gas Board, whose Home Advisors will give advice.

b) Moving the controls on the actual fire is seldom an option and it may be necessary to advise the client to replace a fire with low controls by one with high controls. This is not something the Social Work Department will fund.

c) Where a client is unable to reach the gas supply tap, (not the control on the appliance) it may be possible to move the tap to a more appropriate position. This would be at the client's own expense.

d) Making any modification to a gas fire is potentially hazardous. Any modifications that affect the gas flow should only be done by a CORGI registered contractor.

e) For people with dementia, it is appropriate to consider the provision of an isolator or other suitable alternative on the inflow pipe to a fire. Any CORGI registered contractor could fit this.

N.B Local authority grant provision is only available to replace existing facilities. The social work department does not contribute.

Refer to appendix for regulations that apply to rooms used for sleeping in which have gas appliances.

8.2 Standing Stairlifts

Description: -
Stairlifts for use Standing for those with conditions severely affecting sitting abilities arthrodesis etc.

3 Stairlifts for use with Wheelchairs

- Client is unable to transfer to a stairlift with a seat.
- Progressive disability makes further transfer difficulties likely.
- Environmental conditions may preclude this.

Criteria -

- The client cannot negotiate stairs or is unsafe doing so, even with additional stair rails.
- The client does not have access to internal essential facilities of bathroom and bedroom, nor can accessible facilities be created.

- It is medically contra-indicated for the client to negotiate stairs.

N.B A stairlift would not normally be installed on a common stair.

Factors To Consider

a. Poor sitting/standing balance due to medical reason.
b. Client is confused or spatial orientation problems are present.
c. Severe epilepsy.
d. In some instances, multiply handicapped children.
e. Anxiety factor unresolved by trial use.

9. Non-Essential Adaptations

9.1 Step lift
9.2 Through Floor Lifts

These adaptations are classified as non-essential as other options could be explored and provided for a person which may include rehousing as the property may be unsuitable for adaptations (if 2 storey multiple apartment)

In *some* circumstances, if clients wish to adapt their owner-occupied property with a through floor lift, the department *may* provide a contribution to this through a direct payment. The contribution would amount to the cost of a suitable alternative i.e., ramp/stairlift

9.1 Step lift

Description – powered platform lifts for internal or external access.

Criteria-

- All other options must be explored before consideration of a step lift will be considered including rehousing.
- Where there is insufficient space to provide a ramp and the client is unable to access the property or to reach internal essential facilities.
- It is medically contra-indicated for the client to climb steps or the client's functional ability no longer allows them to climb steps even with rails on both sides.
- To overcome differing ground levels which are inappropriate to ramp due to gradient or lack of space a step lift may be a solution.

Factors To Consider

a. The supplier must take account of Health & Safety
b. Client needs to be made aware of the level of noise.

c. Where there is a possibility of vandalism it may not be considered appropriate to make this installation.
d. Safety and access for others not using the steplift.
e. Weight limit of the steplift.
f. Weatherproof power supply if external site.

9.2 Through Floor Lifts

Description: - A lift that transports people through floors.

Criteria -

- Used where stairlifts are contra-indicated by the person's physical condition
- The stair is unsuitable for a stairlift.
- This is a long-term option used where the persons condition is static or deteriorating

Factors To Consider

a) Re-housing should be considered in the first instance
b) The layout of the house, the position of rooms and the availability of a space on the ground floor with a suitable space above.
c) The loss of essential space for the household.
d) The size of the wheelchair and therefore the size of the lift.
e) If there is space for a bedroom downstairs but no WC/bathing facilities it may be more cost effective to provide a ground floor WC/shower.
f) The capability of the user - most lifts are designed for single occupancy and therefore the carer cannot travel with the user.
g) In some instances, a through floor lift may be more cost-effective than a stairlift.

Appendix One – Painting and Decorating

When an adaptation is undertaken by East Lothian Council, the decoration offered is as listed below. East Lothian Council will only pay for basic decoration.

1. Internal banister

A wooden rail fixed to a back plate and plugged and secured to walls. No varnish or paint supplied.
Metal rail – one coat of paint.

2. External rails at steps or on a ramp

Metal Handrail – one coat of black paint.

3. Rehanging doors/sliding doors and removing doors

No decoration will be undertaken. This is the responsibility of the householder.

4. Walls e.g., Widen Doorways or Hallway

Structural damage will be made good up to plaster level. This wall will be decorated to a minimal standard. If the wall is rough finished, wood chip and one coat of emulsion paint is deemed sufficient. If the wall is smooth finished one coat of paint only is applied.
N.B. The client may elect to undertake alternative decoration without the department's assistance.

5. General Extensions

Walls and Ceiling – Basic decoration is undertaken within the tender i.e., one coat of paint.
Doors and Windows – Basic decoration is undertaken within the tender i.e., one coat of paint.
Toilet – Walls and ceilings – basic decoration is undertaken within the tender i.e., one coat of paint.
Shower-rooms –
Walls: - One coat of paint on affected walls. The regulation area around the shower will be covered with wall boarding. Should the client wish a more expensive wall covering/tiling, the client will pay the difference.
Ceiling: – basic decoration, one coat of emulsion.
Floor Covering – No additional material will be provided e.g., vinyl/carpet.

6. Downstairs Toilet

If the adaptation is to the existing accommodation, we will carry out basic decoration and make good the affected areas.

7. Shower in Existing Accommodation

If we remove the bath and replace it with a shower, we will make good the plaster and coat with one layer of paint.

Water-resistant board will be used to cover the regulation area around the shower. If you would like a more expensive covering, for example, tiling, you will have to pay the difference.

Appendix Two – Reinstatement

When a piece of equipment is no longer required by the client and is being removed the following level of reinstatement will be undertaken by East Lothian Council.

10. Bath Hoist- floor fixed

When a bath hoist is removed East Lothian Council will not take responsibility to make good the floor covering.

11. Specialist shower cubicle or combined shower/toilet unit.

If the alteration involves installing a Shower/Toilet unit or similar in a room other than the bathroom East Lothian Council will consider removing it and sealing off the plumbing.
We will not undertake redecoration.

12. Fixed Overhead Hoists

Within one room - If we remove a hoist and track, we will make good to plaster level and cover with one coat of paint.
Inter room - Remove hoist and track, we will make good structural damage to plaster level and cover with one coat of paint to affected walls.

13. Radiators

It may be necessary to move a radiator to enable equipment to be installed. Under these circumstances East Lothian Council may pay for the radiator move but will not take responsibility for redecoration.

N.B. If the equipment for disability is removed East Lothian Council will not resite the radiator to its original position.

14. Stairlifts

When a stairlift is removed East Lothian Council will not take responsibility to make good the floor covering.

If the stair is left without a banister i.e., contravening building regulations East Lothian Council will reinstate the banister.

Where possible the client should store the existing handrail for reinstatement at a later date.

Where the stair has been altered and the removal of the lift would leave the stair in a dangerous state, East Lothian Council will reinstate the stairs to comply with building regulations.

15. Steplifts

When a steplift is removed, steps will be reinstated. If they rise more than 600mm above the ground, we will provide one rail. If an unguarded platform is left, we will provide rails.

16. Through Floor Lift

When a vertical lift is removed East Lothian Council will reinstate the floor and ceiling. One coat of paint will be applied to the whole ceiling.

We will not replace floor coverings. The carpet needs to be carefully cut and stored for future replacement.

If the lift was within a room the wall will be made good to plaster level and one coat of paint applied on the affected wall. We are unable to match existing decoration.

17. Specialist W.C. with automatic wash and dry operation

When you no longer require the specialist toilet, we must remove it and replace with a standard W.C. Scottish Water must be informed that the closomat has been removed.

N.B. It is the client's responsibility to store the original W.C. for reuse whenever possible.

18. Temporary removal of equipment to undertake maintenance within the home

If you have a piece of equipment removed for any reason (e.g., new carpets) you will be responsible for the cost of reinstatement of the equipment. Specialist equipment must be removed and refitted by an approved contractor.

East Lothian Rehabilitation Service
Community Occupational Therapy Team
Eligibility Criteria for Assessment, Equipment & Adaptations September 2023

This eligibility criteria has been developed to be used as a guidance tool for all Occupational Therapists in helping to determine eligibility criteria for provision of Equipment and Adaptations following Occupational Therapy assessment and intervention.

The criteria is based on East Lothian Councils eligibility criteria that uses Critical/Substantial/Moderate and Low. This helps clinicians and clients receiving services understand the rationale behind whether they are eligible to receive a service.

This specific guidance has been further developed and broken down into very specific Occupational Therapy areas of need. It should be assumed that when clients have been recommended provision of maintainable equipment and/or a major adaptation, rehabilitation will have already been explored and exhausted and therefore moved to the next stage in provision of equipment/adaptations.

It is important to remember that all people with a physical impairment or long-term condition are entitled to an assessment of their needs. (Chronically Sick and Disabled Persons Act 1970)

HEALTH & SAFETY/ACUTE ILLNESS	CRITICAL (Life or Death	SUBSTANTIAL	MODERATE	LOW
	URGENT/SOON Requests (usually seen within 48 hours – 10 days): Prevention of Admission / Reduce risk of carer stress /breakdown in care arrangements and requires immediate stabilisation of situation at home. If clients fall under Moderate / Low they are likely to be placed on Routine Waiting Lists for Assessment.			
Prognosis	Terminal Diseases, with rapid deterioration likely within less than 1 month, client is at risk with medical (or other) emergencies, e.g., alarm needed, critically severe effects of the illness will be present. E.g., Lung Cancer	Very poor prognosis, where deterioration is likely within the near future; with very severe effects of the illness, client is at risk with medical (or other) emergencies, e.g., alarm needed.	Poor prognosis, where client is at risk with medical (or other) emergencies, e.g., alarm needed. Illness at risk of deterioration in foreseeable future if help is not given.	Few health problems, or minor symptoms. Limited risk to independence within foreseeable future.
Environmental Hazards e.g., stairs / steps	All areas of hazard are unavoidable to access essential rooms and facilities. Client is totally unable to negotiate immediate environment safely. Unable to move independently, and safely.	Majority of hazards are unavoidable whilst accessing essential rooms and facilities. Unable to move independently and safely, causing concern for safety without assistance.	Many hazards can be avoided temporarily e.g., bed downstairs/ commode. Presents only limited difficulty, but the risk to independence in the foreseeable future is present.	1-2 hazards are avoided temporarily, having minor impact/distress on the client. Limited difficulty and risk to independence in the foreseeable future.
Risk of Fall	Client is at imminent risk of both a serious fall, when performing an essential daily activity, as well as likely hospitalisation. Likely loss of independence. **Risk of fracture or previous fracture from fall, and/or previous fall on the stairs or other**.	At a significant risk of fall and therefore loss of independence within near future. Equipment provision, e.g., rails etc, could increase safety**. Falls experienced at some frequency**	At risk within the foreseeable future, if equipment is not provided or advice given. Likely risk loss of independence in long term. **Some risk of falling during specific activities.**	Low risk of fall, and loss of independence. Basic Equip provision and advice would not greatly alter the level of risk encountered on a daily basis. Low **Risk of falls but not frequent falls**
Carers	Responsibility is too 'great to manage, and carer is at high risk of severe injury to themselves or others, where carer has very low or no support network. Or No carer present or an imminent risk of breakdown of current care routine. Critical neglect occurring/ high risk from Carer.	Carer has significant physical difficulties, and is at risk of injury in near future, where carer has very low support network. Or Risk breakdown of care in near future. Neglect occurring/ Risk of neglect in near future.	Manages with difficulty, or unable to manage some aspects or role. Limited support network is available for carer, resulting in a possible risk of breakdown of care in foreseeable future. Risk of neglect in foreseeable future.	Carer has good support network and has little difficulty and no significant risk of breakdown in the foreseeable future. No/minimal risk of neglect in the foreseeable future.
Understanding Risks (Cognition/memory)	Very poor cognition/ memory. No understanding of risks, and client is constantly putting themselves at risk, of severe injury /accident. Total lack of independence, due to unsafe nature of behaviour	Usually very poor cognition/ memory. At risk for majority of tasks, limited understanding but still putting self at significant risk, resulting in a loss of independence now or in the near future.	Sometimes cognition/ memory very poor. Partial understanding or risks, with awareness causing intermittent stress now or in foreseeable future. Client lost much of their independence due to inability to do many tasks safely	Sometimes cognition/ memory very poor. Cautious of risks, client has clear understanding and will be able to contact the department when their situation deteriorates. Level of risk may cause client intermittent stress now or in foreseeable future.

Make needs known	Unable as client is unaware of their needs, or their full extent. Review needed.	Client is not aware of a majority of their needs and is not likely to notify of needs. Review needed.	Likely to notify of needs, as client understands the significance of most needs and their extent.	Can/will make needs known. Review not necessary.
Arm and hand Function	None. No weight bearing.	No grip. Excessive tremor. No weight bearing.	Poor grip. Limited weight bearable. Joint protection (preventative).	Some discomfort, but possible.
M & H Transfers: Chair	Non-weight bearing. Completely unable - needs physical assistance	Able with assistance, but with Great difficulty. Equip/ carer needed.	Able with assistive equipment.	Able to transfer with difficulty, but with no foreseeable risk to independence.
Bed	Completely unable - need physical assistance	Able with assistance, but with great difficulty. Equip/ carer needed	Able with assistive equipment.	Able to transfer with difficulty, but with no foreseeable risk to independence.
Bath / Shower	Non-Critical in OT: People have the ability to be washed down – i.e., there is an alternative	Able with assistance, but with great difficulty. Equip/ carer needed. **Some risk of breakdown in skin integrity.**	Able with assistive equipment.	Able to transfer with difficulty, but with no foreseeable risk to independence.
Toilet	Completely unable - need physical assistance	Able with assistance, but with great difficulty, Equip/ carer needed.	Able with assistive equipment.	Able to transfer with difficulty, but with no foreseeable **risk** to independence.
Wheelchair	Completely unable - need physical assistance	Able with assistance, but with great difficulty. Equip /carer needed.	Able with assistive equipment.	Able to transfer with difficulty, but with no foreseeable risk to independence.
Adult Support & Protection	Client at critical risk and without Occupational Therapy assessment, risks are increased. M & H related / Carer stress / Challenging behaviour etc	Client at substantial risk without intervention	Client at moderate risk – may still need assessment and intervention, ensure full discussions with senior to ensure routine is appropriate and other risk needs met by SW.	Client at no Occupational therapy risk – may need referring back to Social Work
Mental Health Issues / Challenging Behaviour / Substance Misuse	Person with mental health issues/challenging behaviour/substance misuse issues or carer is at critical risk of harm/injury. Ensure correct team involvement as may be better placed with specialist team if not already involved.	Person with mental health issues/challenging behaviour/substance misuse issues or carer is at moderate risk of harm/injury. Ensure correct team involvement as may be better placed with Mental Health / Paediatrics/ Learning Disability	Client at moderate risk – may still need assessment and intervention, ensure full discussions with senior to ensure routine is appropriate and other risk needs met by more appropriate teams.	Client at no Occupational therapy risk – may need referring back to more appropriate teams.

PERSONAL & DOMESTIC ACTIVITIES OF DAILY LIVING (PADL & DADL)	CRITICAL (Life or Death	SUBSTANTIAL	MODERATE	LOW
Most PADL activities will not come under CRITICAL unless at risk of to health (incontinence – skin integrity and fluid and nutritional intake).				
Dressing	Non-critical in OT.	Total inability/ Unable to do the majority of the task. No carer. Lack of independence	Cannot do some/ many dressing tasks, needs some assistance. Some risk to independence in the foreseeable future	With difficulty can complete task but limited risk. Unable to do 1- 2 aspects of the task independently.
Hair	Non-critical in OT.	Total inability to wash or groom. Lack of independence. Major risk to independence in the near future.	Cannot do some of task, needs some assistance. Some risk to independence in the foreseeable future.	With difficulty can completed task but limited risk. Unable to do 1-2 aspects of the task independently.
Bathing	Non-critical in OT.	Medical need for maintained personal hygiene Unable to strip-wash? Some risk to independence in the foreseeable future. Challenging behaviour	Non-medical need. Unable to strip wash? Some risk to independence in the foreseeable future.	Able to strip wash, with difficulty, but can complete task but limited risk. Unable to do 1-2 aspects of the task independently.
Toileting	Double incontinence No carer Lack of independence	Incontinence. Only informal carer. i.e., New Hip Replacement Major risk to independence in the near future.	Cannot do some of the tasks, needs some assistance to fulfil task. Some risk to independence in the foreseeable future.	With difficulty can complete task but limited risk. Unable to do 1-2 aspects of the task independently.
Oral Care	Non-critical in OT.	Total inability, no carer. Lack of independence. Major risk to independence in the near future.	Cannot do some of the tasks, needs some assistance to fulfil task. Some risk to independence in the foreseeable future	With difficulty can complete task but limited risk. Unable to do 1-2 aspects of the task independently.
Shaving	Non-critical in OT.	Total inability, no carer. Lack of independence. Major risk to independence in the near future.	Cannot do some of task, needs some assistance to fulfil task. Some risk to independence in the foreseeable future.	With difficulty can complete task but limited risk Unable to do 1-2 aspects of the task independently.
Feed Self	Non-critical in OT, except when there is a malnutrition issue	Total inability, no carer. Major risk to independence in the near future.	Cannot do some of these tasks. Needs some assistance to fulfil task Some risk to independence in the foreseeable future	With difficulty can complete task but limited risk. Unable to do 1-2 aspects of the task independently.

Hand / Toenail care	Non-critical in OT	Total inability to wash or groom. Lack of independence. Major risk to independence in the near future.	Cannot do some of task, needs some assistance. Some risk to independence in the foreseeable future.	With difficulty can completed task but limited risk. Unable to do 1-2 aspects of the task independently.
Access Facilities	Total inability, nor carer. Need adaptation of property e.g., sink/ light switches/plug, socket/ taps/ appliances Lack of independence Health and safety risk	Cannot do majority of the tasks Informal carer- needs adapt. e.g., sink/ light switches/ plug socket taps/ appliances Major risk to independence in the near future	Formal/ informal care. Needs some assistance - equipment e.g., **sink/** light switches/ plug socket/ taps/ appliances. Some risk to independence in the foreseeable future	With difficulty but limited risk to independence. Carer present. e.g., sink/ light switches/ plug socket/ taps/ appliances Unable to do 1-2 aspects of the task independently.
Food Prep	Total inability, no carer Lack of independence	Cannot do majority of the task. Major risk to independence in the near future.	Limited risk. Needs some assistance. Some risk to independence in the foreseeable future.	With difficulty but limited risk to ind. Unable to do 1-2 aspects of the task independently.
Prepare Drink	Total inability, no carer Lack of independence	Cannot do majority of the task. Major risk to independence in the near future.	Limited risk. Needs some assistance. Some risk to independence in the foreseeable future.	With difficulty but limited risk to ind. Unable to do 1-2 aspects of the task independently.
Do Housework	Non-critical in OT, as other arrangements can be made ie care or other support.	None or minimal can be done, with great difficulty. Major risk to independence in the near future. No assistance.	Limited risk. Needs some assistance. Some risk to independence in the foreseeable future.	With difficulty but limited risk to ind. Unable to do 1 - 2 aspects of the task independently.
Shopping	Non-critical in OT, as alternative arrangements can be made i.e., care or other support.	Total inability/ cannot do majority of the task. No carer present. Major risk to independence in the near future.	Limited risk. Needs some assistance. Some risk to independence in the foreseeable future.	With difficulty but limited risk to ind. Unable to do 1- 2 aspects of the task independently.
Laundry	Non-critical in OT. As above	Total inability/ cannot do majority of the task. No carer present. Major risk to independence in the near future.	Limited risk. Needs some assistance. Some risk to independence in the foreseeable future.	With difficulty but limited risk to ind. Unable to do 1- 2 aspects of the task independently.

AUTONOMY	CRITICAL (Life or Death	SUBSTANTIAL	MODERATE	LOW
Get to toilet	Unable to mobilise to access toilet on time. Equip could not be provided temporarily.	In majority of cases is unable to get to on time. Temporary Equipment Loan.	Sometimes will not. Temporary Equipment Loan	Occasionally (1-2 times) has been unable.
Access in and out of home	Non - critical in OT.	No access possible. Very difficult even with assistance. Essential need.	Access difficult but possible with assistance - Non-essential need.	Limited mobility outdoors.
Only able to Few steps	Totally impossible, with no alternative. Essential need.	Possible with assistance, but still with much difficulty. Non-essential need.	With difficulty, but possible with equipment provision. Non-essential need.	With difficulty but with no risk of accident within the foreseeable future.
Flight of stairs	Totally impossible, with no alternative. Essential need.	Possible with assistance, but still with much difficulty. Non-essential need.	With difficulty, but possible with equipment provision. Non-essential need.	With difficulty but with no risk of accident within the foreseeable future.
Use walking frame	Non - critical in OT.	Cannot access essential facilities due to frame, and no temporary options.	Diff. Moving through doors etc. Managing with difficulty.	Able to do but is awkward.
Wheelchair: Electric	Internal access to essential facilities. Cannot manage with interim measures for short period.	Difficulty accessing a majority of essential facilities.	Difficulty accessing some facilities, i.e., Front/ Garden (non-essential)	Unable to access 1-2 non-vital facilities.
Self-propelled	Internal access to essential facilities. Cannot manage with interim measures for short period.	Difficulty accessing a majority of essential facilities.	Difficulty accessing some facilities, i.e., Front/ Garden (non-essential)	Unable to access 1-2 non-vital facilities.
Attendant propelled chair	Health/ ability of carer /Threshold. Very poor mobility.	Carer able but with difficulty. Poor mobility indoors.	Some problems accessing some non-essential facilities.	Unable to access 1-2 non-vital facilities.

Hospitalisation / Bed Blocking	Would require imminent admission to residential/hospital care without support.	Assistance will help to avoid the risk/ need.	Hospital likely if no assistance in the foreseeable future.	Low risk of hospitalisation in the foreseeable future.
Social situation / Arrangements	Non – critical in OT	Alone - No social support network. No family/ relationship. No carer present. Health and Safety risk. No formal carers present.	Social network at risk in the foreseeable future of breakdown, causing health and safety risk. Family present but none acting as carers.	Family present as informal carers. Social network is wide and at no Risk of breakdown in the Foreseeable future.
Reliance / dependence on others	Fully dependant on others. Total lack of independence now or in the near future. No carer present.	Significant risk to independence. Problems, e.g., inability to hear doorbell to let carer in.	Informal carer/ family.	Formal carer/ family

Inv. In Family and wider life	CRITICAL (Life or Death	SUBSTANTIAL	MODERATE	LOW
Paediatric Cases	Most Paediatric cases will also have links with NHS Lothian Childrens' service. Please ensure work isn't already being carrie d out by these teams. Rehabilitation will be progressed via NHS Lothian Teams but longer-term adaptation work will be progressed via Community Occupational Therapy / ELRS Teams			
Lifestyle Preferences / Cultural Needs	Non-critical in OT.	Serious risk of loss of independence in near future. Unable to maintain religious role/ social depression/ isolation. Majority of needs not met, may damage client's mental/physical health, due to exclusion. Very high importance to client.	May cause depression or isolation in the foreseeable future, as some of client's religious/ cultural needs are unmet.	1-2 needs are not fulfilled but have little damage on client. Client does not hold these activities in a high importance.
Social role	Non-critical in OT.	Most of social role not possible. Cannot be sustained without help. Exclusion is beginning to damage client's mental and physical health in near future. Risk of loss of independence and social exclusion is likely in the near future, causing major distress. Social role is a major part of client's life.	Risk of social exclusion is likely in the foreseeable future, as some of the client's previous social role is no longer possible without assistance. Social exclusion will cause limited distress to client.	Low risk of social exclusion in the foreseeable future. Wide social support group.
Relationships	Non-critical in OT.	Major difficulties with maintaining a relationship. Sexual function not possible/ highly difficult and likely to break down in near future due to unsustainable levels of stress. Health at possible risk in near future due to stress/ distress.	Some difficulties maintaining a relationship, but could be overcome with assistance, equipment provision and advice. Possible risk of breakdown in foreseeable future causing damage to client's health.	Client's relationships are not seriously put at risk as a result of disability. A limited stress is put on others in situation, helped by equipment provision/ advice.
Family role	Non-critical in OT.	Cannot be sustained without assistance. Puts health/well-being at risk, due to social exclusion and major distress. Immediate loss of independence. Puts unacceptable strain on others. Many members are dependent on client, so Vitally important	Could be sustained without help. Puts health at limited risk of exclusion. Loss of independence possible in the foreseeable future due to unacceptable strain on others.	Could be sustained without help. Puts health at very low risk of exclusion. Loss of independence limited in foreseeable future.

Support Systems	Non – critical in OT	Cannot be sustained without help, puts health at risk, due to social exclusion. Significant risk to breakdown in near future. Unacceptable strain on others - imminent danger of relationships breaking down. No support systems in place - client is isolated-dependent for social integration.	Limited risk to support systems in the foreseeable future. Client not fully dependent on support. Partial isolation.	Low risk to support systems in future. Could be sustained without intervention. Client not really dependant on support. Limited isolation.
Education	Non – critical in OT	Activity is putting health at some risk - exclusion and therefore distress cannot be stopped without some assistance. Loss of independence possible in near future. Essential need.	Limited risk of exclusion /distress/ loss of independence in the foreseeable future. Unable to perform some aspects of the task.	Low risk of exclusion/ distress/ loss of independence in the foreseeable future. Unable to perform 1-2 aspects of the task.
Leisure	Non – critical in OT	Cannot be sustained without some help. Puts physical mental health at risk, due to distress caused by exclusion. Loss of independence possible in near future. Essential need.	Limited risk of exclusion/ distress/ loss of independence in the foreseeable future. Unable to perform some aspects of the task.	Low risk of exclusion / distress/ loss of independence in the foreseeable future. Puts health at very low risk due to exclusion from vital leisure role.
Work	Non – critical in OT	Cannot be sustained without some help. Puts physical/ mental health at risk, due to distress caused by exclusion. Loss of independence possible in near future. Essential need.	Limited risk of exclusion/ distress/ loss of independence in the foreseeable future. Unable to perform some aspects of the task.	Could be sustained with difficulty, without help. Puts health at very low risk of exclusion.

i. Near future = Within three months
ii. Foreseeable future= Within the next 12 months

East Lothian Council

Appendix 5

ELIGIBILITY CRITERIA CHECKLIST
Community Care Services

Name: _____ Date of Birth: ____ /_____ /____

This form must only be completed following an assessment or review to determine if a person has social care needs that are eligible for services arranged or provided by East Lothian Council

How the Eligibility Criteria are used

- Alternatives to the need for social care assistance **must** always be explored during the assessment to include the contributions from family / wider community / voluntary sector / other agencies.
- A person is **only** eligible for social care services where needs are identified above the threshold line and where there is no -one else willing / able / appropriate to assist.
- If needs are identified below the threshold line then information and advice about available services **must** be given.
- The emphasis should be to arrange short term interventions to enable people to be independent where possible.
- Peoples' needs and risks alter over time. Needs will be reviewed to check whether there are eligible needs.
- The assessment / review will have identified the interaction between **all** a person's needs and risks, the individual's views and attitudes towards the risks and the predictability and time frames within which they are likely to occur. This information will inform decision making on the Checklist about the level of seriousness of the risks in terms of harm or danger and the level of impact to an individual's independence.

Definitions of Levels of Risk

Critical:	The risk of major harm / danger to a person or major risks to independence.
Substantial:	The risk of significant impairment to the health and well being of a person or significant risk to independence.
Moderate:	The risk of some impairment to the health and well being of a person or some risk to independence.
Low:	Promoting a person's quality of life or low risk to independence.

Section 1: Needs Relating to Your Physical and Mental Health

Critical	• You have major health problems which cause immediate life threatening harm or danger to yourself or others and need social care support. • Serious abuse or neglect has occurred or is strongly suspected and you need protective intervention by Social Work (includes financial abuse and discrimination).
Substantial	• You have significant health problems which cause significant risks of harm or danger to yourself or others either now or in the near future and need social care support. • Abuse or neglect has occurred or is strongly suspected in the near future and you need social care support (includes financial abuse and discrimination).
Threshold for Services	
Moderate	• You have some health problems indicating some risks to your independence and / or intermittent distress either now or in the foreseeable future.
Low	• You have a few health problems indicating low risks to your independence.

Note: Mental Health within Critical and Substantial: includes severe enduring mental illness / regular episodes of severe mental illness, acute mental breakdown, life threatening or serious chronic substance misuse / neglect.

Section 2: Needs Relating to Your Personal Care / Domestic Routines / Home Environment

Critical	• You are unable to do vital or most aspects of your personal care causing a major and immediate harm or danger to yourself or others **or** major and immediate risks to your independence and you need social care support. • You are unable to manage vital or most aspects of your domestic routines causing major and immediate harm or danger to yourself or others **or** major and immediate risks to your independence and you need social care support. • You have an extensive / complete loss of choice and control over vital aspects of your home environment causing major and immediate harm or danger to yourself or others **or** major and immediate risks to your independence and you need social care support.
Substantial	• You are unable to do many aspects of your personal care causing significant risk of danger or harm to yourself or others **or** significant risks to your independence either now or in the near future and you need social care support. • You are unable to manage many aspects of your domestic routines causing significant risk of harm or danger to yourself or others **or** significant risks to your independence either now or in the near future and you need social care support. • You have substantial loss of choice and control managing your home environment causing a significant risk of harm or danger to yourself or others **or** a significant risk to your independence and you need social care support.
Threshold for Services	
Moderate	• You are unable to do some aspects of your personal care indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your domestic routines indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your home environment indicating some risk to your independence either now or in the foreseeable future.
Low	• You have difficulty with one or two aspects of your personal care, domestic routines and / or home environment indicating little risk to your independence.

Section 3: Needs Relating to Your Family and Social Responsibilities

Critical	• You are unable to sustain your involvement in vital or most aspects of work / education /learning causing a major and immediate loss of your independence and you need social care assistance. • You are unable to sustain your involvement in vital or most aspects of family / social roles and responsibilities and social contact causing major distress and / or immediate loss of your independence and you need social care support.
Substantial	• You are unable to sustain your involvement in many aspects of work / education / learning causing a significant risk to your independence either now or in the near future and you need social care assistance. • You are unable to sustain your involvement in many aspects of your family / social roles and responsibilities and social contact causing significant distress and / or risk to your independence either now or in the near future and you need social care support.
Threshold for Services	
Moderate	• You are unable to manage some aspects of your involvement in work / learning / education indicating some risk to your independence either now or in the foreseeable future. • You are unable to manage some aspects of your family / social roles and responsibilities and social contact indicating some risk to your independence either now or in the foreseeable future.
Low	• You have difficulty undertaking one or two aspects of your work / learning / education / family and / or social networks indicating little risk to your independence.

Section 4: Carers

Critical	• Your carer has major physical / mental health difficulties due to the impact of their role as a carer causing immediate life threatening harm or danger to themselves or others and they need social care support. • There is a complete breakdown in the relationship between you and your carer and your carer is unable to continue caring or has difficulty sustaining vital or most aspects of their caring role. • Your carer is unable to manage vital or most aspects of their caring / family / work / domestic / social roles and responsibilities and needs social care support.
Substantial	• Your carer has significant physical / mental health difficulties due to the impact of their role as a carer causing significant risk of harm or danger to themselves or others either now or in the near future and they need social care support. • There is a significant risk of breakdown in the relationship between you and your carer and your carer is unable to sustain many aspects of their caring role either now or in the near future. • Your carer is unable to manage many aspects of their caring / family / work / domestic / social roles and responsibilities either now or in the near future and needs social care support.
Threshold for Services	
Moderate	• Your carer is unable to manage some aspects of their caring / family / domestic / social roles either now or in the foreseeable future.
Low	• Your carer has difficulty undertaking one or two aspects of their caring / domestic role.

Glossary of Terms

Near future:	Up to three months.
Foreseeable future:	Up to twelve months.
Health:	Includes physical, sensory, learning, behaviour, cognitive disabilities and impairments, mental health.
Social Care Support:	May be short term, time limited or ongoing. It includes care, assistance, personal support, enabling, supervision and equipment arranged by East Lothian Council
Personal Care:	Any activity that requires close personal and physical contact or personal support from another person and which does not fulfill a medical function.
Domestic Routines:	Support required to assist a person to manage their living environment and which does not involve personal or intimate care.
Home Environment:	Includes mobility, access, accommodation, ability to manage money and so on.

If you or your carer are unhappy with the decisions recorded, please discuss this with the care manager or their manager. If you are still unhappy, please ask the care manager for a copy of the complaints procedure.

For office use:

Completed by: _____ Date: ___/____/___

Copy to service user / carer? Yes ☐ Date: _____ No ☐ Reason: _____