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# BMJ Open

## Improving access to primary care and annual health checks for people who have a learning disability. A multi-stakeholder qualitative study

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31  
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1  
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3 **34 Abstract**  
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6 **35 Objectives:** To investigate the views of key stakeholders on how access to primary care in  
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8 **36** general practice settings might be improved for people with learning disabilities. Further to  
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10 **37** explore how inequalities/barriers in specific areas including annual health checks might be  
11  
12 **38** addressed.

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14 **39** *Design:* A qualitative study design was utilized with data collected during focus groups,  
15  
16  
17 **40** interviews and surveys; data analysis was thematic and informed by stakeholder consultation.  
18  
19 **41** Processes to facilitate quality included triangulation of stakeholder perspectives/data collection  
20  
21 **42** methods, and checking interpretation of findings with participants.

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23  
24 **43** *Setting:* UK regional services including learning disability organisations, general practitioner  
25  
26 **44** clinical practice networks and supported housing organisations.

27  
28 **45** *Participants:* Sixteen people participated in the study: 6 people with learning disabilities  
29  
30 **46** participated in two focus groups; 4 relatives completed interviews/surveys; 8 GPs, practice  
31  
32 **47** nurses and supported housing managers participated in interviews.

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35 **48** *Results:* Four overarching themes describing approaches to improve primary care access for  
36  
37 **49** people with learning disabilities were identified including: prioritisation, proactivity,  
38  
39 **50** personalisation and prevention. Definitions of themes were described and illustrated with  
40  
41 **51** quotes; a model was developed showing interconnection between themes, subthemes and  
42  
43 **52** service characteristics. Ten recommendations were developed informed by the thematic  
44  
45 **53** analysis, stakeholder consultation including people who have a learning disability, and  
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47 **54** research/primary care guidance.

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51 **55** *Conclusions:* All stakeholders identified problems regarding the ways in which primary care  
52  
53 **56** interfaces are misaligned with the needs of people with learning disabilities. The  
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55 **57** recommendations informed by all stakeholders can be used to guide service development for  
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57 **58** better service user/service provision fit to improve access to primary care for people with  
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3 59 learning disabilities. Future research should explore professionals' understanding of reasonable  
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5 60 adjustments.  
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3 **63 Article Summary: *Strengths and limitations of this study***  
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- 5  
6 **64** • Qualitative data were collected from 16 key stakeholders (people with a learning  
7  
8 **65** disability, relatives, general practitioners, practice nurses and sheltered housing  
9  
10 **66** managers) on ways to improve primary care access for people with learning disabilities  
11  
12 **67** • Stakeholder consultation informed study design and interpretation of the research  
13  
14 **68** findings  
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16  
17 **69** • We used convenience sampling and the number of participants was small though this  
18  
19 **70** is appropriate for qualitative designs  
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22 **71** • Different methods of data collection were utilized, perspectives were triangulated  
23  
24 **72** across key stakeholders and interpretation of the research findings was checked with  
25  
26 **73** research participants  
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29 **74**

30  
31 **75** Keywords: primary care; learning disabilities, health checks, health inequalities  
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33 **76**

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35 **77** **Word Count:** 4000  
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## 78 **Introduction**

79 People with learning disabilities (or intellectual disabilities) experience significant health  
80 inequalities, and a higher burden of chronic disease and mortality compared to the general  
81 population.<sup>1-3</sup> During the COVID-19 pandemic people with learning disabilities were at  
82 increased risk of hospitalization and mortality compared to those without a learning disability.

83 <sup>4</sup> Given health vulnerabilities/inequalities, prioritizing the health needs of people with learning  
84 disabilities is crucial <sup>5</sup> and guidance has been developed to address this; in the United Kingdom  
85 (UK) recommendations include annual health checks, learning disability registers and  
86 reasonable adjustments. <sup>6-8</sup>

87 Annual health checks can uncover previously unknown conditions, <sup>9</sup> reduce preventable  
88 emergency hospitalizations, <sup>10</sup> allow monitoring treatments and foster continuity of care.

89 Templates for annual health checks are available comprising general/specific assessments and  
90 they are conducted by General Practitioners (GPs) and practice nurses who facilitate access for  
91 people with learning disabilities into healthcare services/systems. <sup>11</sup>

92 Registers and read/diagnostic/SNOMED codes facilitate identifying people attending primary  
93 care who may have a learning disability, however, people may be incorrectly/not coded so  
94 excluded from access to healthcare/adjustments, and methods of identifying people with  
95 learning disabilities in primary care are required. <sup>12 13</sup> Accessibility can be facilitated by  
96 providing information in easy-read, alternative and personalised formats <sup>14 15</sup> and allowing  
97 adequate time for appointments. <sup>16</sup> Other ways to reduce barriers to primary care for people  
98 with learning disabilities include staff training; <sup>17</sup> and improving comprehensibility of health  
99 assessment/questionnaires. <sup>18</sup>

100 Despite previous initiatives evidence suggests barriers/inequalities in primary healthcare  
101 persist: women with learning disabilities are less likely than those without to have cervical



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3 102 cancer screening.<sup>19</sup> Further, while prevalence of long-term conditions in primary care (e.g.  
4  
5 103 epilepsy, diabetes), is higher among people with learning disabilities, best-practice condition-  
6  
7 104 management indicators are lower relative to the general population.<sup>20</sup> Barriers to primary care  
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10 105 for people with learning disabilities, include fear, limited carer awareness of health problems,  
11  
12 106 <sup>21</sup> and lack of evidence-based lifestyle interventions (e.g. obesity prevention) combined with  
13  
14 107 systems/organisational barriers to implementation.<sup>22</sup> A review of service user/carers  
15  
16 108 perspectives has identified six facilitators/barriers to people with learning disabilities accessing  
17  
18 109 primary health care including: involvement in healthcare decision-making, time,  
19  
20 110 knowledge/awareness, training, communication and fear/embarrassment.<sup>23</sup> An involved/active  
21  
22 111 role for people with learning disabilities in healthcare interactions is required <sup>24</sup> and UK  
23  
24 112 national guidance recommends primary health teams identify a learning disabilities expert to  
25  
26 113 be a champion, and share good practice.<sup>25</sup>

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31 114 The aim of the study was build on previous research using qualitative methods to elicit key  
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33 115 stakeholder views on how GP primary care access might be improved for people with learning  
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35 116 disabilities.

## 36 37 38 39 117 **Methods**

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41  
42 118 A qualitative study design was utilized with data collected during focus groups, interviews and  
43  
44 119 surveys; the analytic approach was thematic analysis with an inductive experiential framework  
45  
46 120 informed by stakeholder consultation. Data collection was conducted by the first and second  
47  
48 121 authors (clinical researchers with significant experience in the field of learning disabilities).  
49  
50 122 Data analysis was conducted by the first and last (a clinical academic with significant  
51  
52 123 experience in the field of learning disabilities) authors.

## 53 54 55 124 *Participants*

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3 125 Recruitment was purposive to capture a range of stakeholder perspectives. Inclusion criteria  
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5 126 were adults (>18 years of age) with mild/moderate learning disabilities with capacity to consent  
6  
7 127 to participate in the research. People with learning disabilities were recruited via a UK regional  
8  
9 128 charity providing support for people with learning disabilities and an online health literacy  
10  
11 129 group. Capacity to consent was assessed by the research team using specialist materials.  
12  
13 130 Accessible study information was distributed to people with learning disabilities accessing the  
14  
15 131 online health literacy group; and by the regional charity who informed the research team of  
16  
17 132 people with learning disabilities who met inclusion criteria and expressed interest in  
18  
19 133 participating. Relatives of adults with learning disabilities were recruited via a regional charity  
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21 134 and existing network of contacts who distributed information about the study and researcher  
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23 135 contact details.  
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29 136 GPs, practice nurses and sheltered housing managers were recruited through regional general  
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31 137 practice and learning disability clinical networks.  
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### 34 138 *Data collection*

35  
36 139 Data collection was online after completion of informed consent. Two focus groups were  
37  
38 140 conducted with people with learning disabilities. Data collection from relatives was by  
39  
40 141 interview or survey depending on their preference. The focus groups, interviews and surveys  
41  
42 142 followed the same semi-structured format/topic schedule (Online Supplementary materials:  
43  
44 143 OS1). During focus groups and interviews, probes/prompts were used to elicit detail e.g. can  
45  
46 144 you tell me more about that? Key points from the focus groups with people with learning  
47  
48 145 disabilities were summarized by the researcher and read back to the group to check  
49  
50 146 accuracy/comprehensiveness. Interviews with relatives were audio-recorded and transcribed.  
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55 147 Online semi-structured interviews conducted with GPs, nurse practitioners and sheltered  
56  
57 148 housing managers were audio-recorded and transcribed. The interview schedule (OS2)  
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3 149 comprised five sections: (i) annual health checks (ii) learning disability inclusion tools (iii)  
4  
5 150 barriers to accessing primary care (iv) reasonable adjustments (v) COVID-19.  
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### 8 151 *Patient and Public Involvement*

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10 152 Study documents (consent/information sheets; focus group/interview topic guides) were  
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13 153 developed in consultation with a research advisory group led by people with learning  
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15 154 disabilities. Feedback included to add content, edit/improve wording for clarity, and create a  
16  
17 155 post-participation debrief document. We consulted GPs regarding the interview topic schedules  
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19  
20 156 and received advice on wording/content. Initial review of data indicated that living  
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22 157 arrangements/support can impact access to primary care - this was discussed with a GP and  
23  
24 158 informed our decision to recruit sheltered housing managers as participants.  
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28 159 For consultation/dissemination, an online presentation of preliminary findings was made to a  
29  
30 160 research advisory group led by people with learning disabilities. The recommendations were  
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32 161 sent to a people with learning disabilities-led advisory group, who made suggestions to improve  
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34 162 content/accessibility/readability. Study findings were presented to a GP practice meeting. The  
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37 163 local clinical commissioning group, and regional GP clinical practice network advised on  
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39 164 dissemination.  
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42 165 Ethical approval was provided by Newcastle University Faculty of Medical Sciences Research  
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45 166 Ethics Committee.  
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### 48 167 *Analysis*

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50 168 Thematic analysis was conducted in iterative phases (1) data immersion/familiarisation (2)  
51  
52 169 coding (3) collating/organising data on a coding framework (4) identifying themes (5)  
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54  
55 170 reviewing/revising/confirming themes (6) creating definitions of themes/opposing perspectives  
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57 171 and identifying illustrative quotes.<sup>26 27</sup> A model was developed showing theme  
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3 172 interconnectedness; recommendations were developed informed by thematic analysis findings,  
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5 173 research/primary care guidance and consultation with key stakeholders.  
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8 174 In accordance with qualitative analysis best-practice, trustworthiness was ensured by: (i)  
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10 175 checking interpretation of findings with research participants (ii) triangulating  
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12 176 perspectives/important aspects of the topic by collecting data from different stakeholders using  
13  
14 177 different methods (iii) inviting participants to comment on our summary/interpretation of  
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16 178 findings which is important for credibility.<sup>26 27</sup>  
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## 20 179 **Results**

21  
22 180 Sixteen people participated: comprising 6 people with learning disabilities (2 male; 4 female);  
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24 181 four relatives (all female); and eight GPs, practice nurses and supported housing managers (7  
25  
26 182 female; 1 male). Four themes were identified from the focus groups, interviews and surveys:  
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28 183 prioritisation, proactivity, personalisation and prevention; themes and subthemes are shown in  
29  
30 184 Figure 1. The 4 interconnected themes can be applied to different aspects of primary care  
31  
32 185 service provision, this is described throughout the results and shown in Figure 2. The themes  
33  
34 186 informed development of ten recommendations (TR) (Table 1) referred to throughout the  
35  
36 187 results. Quotes are from people with learning disabilities unless stated otherwise; SHM:  
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38 188 sheltered housing manager.  
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44 189 The study was conducted during the COVID-19 pandemic and it is important to describe this  
45  
46 190 context to the study and the themes. Participants described changes to healthcare delivery  
47  
48 191 including impacts on health checks: 'there was a lot of Facetime consultation' (SHM) and 'we  
49  
50 192 had to put them (health checks) all on hold'. Some changes were adopted longer-term:  
51  
52 193 'Now we've got the tech in place it allows patient choice if somebody finds it more comfortable  
53  
54 194 having a consultation by video/phone'. However, this wasn't suitable in all situations: 'There  
55  
56 195 are bits of health checks that need to be done face-to-face, you can't do a breast or testicle  
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58 196 check over the phone/video'; and long-term impacts of the pandemic were described 'It's been  
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197 detrimental to diet/exercise so general health probably has got worse, I'm worried we're going  
198 to have an explosion in diabetes, obesity and frailty in this population over the months ahead'.  
199 *(Figure 1 around here)*

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Table 1 Ten suggestions for improving annual/yearly health checks for people with learning disabilities

1	<i>Call them 'yearly' health checks</i>	The health check should take place every year, 'yearly'. People should know that this does not stop them from seeing a doctor at other times if they have a health problem
2	<i>Create a supportive practice</i>	Helping the checks work well for people, 'personalisation', and making reasonable adjustments can make a big difference. Creating, seeing, and sharing examples of good practice can improve how we give support. Having a practice champion could help with this
3	<i>Use a screening tool (learning disability inclusion tool)</i>	Screening tools (learning disability inclusion tools) can be used to help understand what people's needs are and/or show if they might have a learning disability. Keeping registers up to date is important
4	<i>Be pro-active!</i>	Contact people to attend and follow-up with them if they do not attend. People need to know why they are being asked to get a health check and what will happen. Check that people have got information in a way that they can understand it
5	<i>Give a personalised offer around appointments</i>	Ask if the check is at a good time for them to come and if it is going to be at a place that they can get to. Offer longer appointment times so that checks are not done in a hurry and find out what extra support people might need.
6	<i>In the appointment speak to the person directly</i>	Even if the person has someone supporting them speak to the person first, about their health. Let the person know what is going to happen and let the person ask questions, even if it takes a bit longer.
7	<i>Provide easy read information or picture-questionnaires</i>	Make co-developed easy read information the same for all practices. Give information about what will happen before the appointment and give people information to take away with them about their health. Use an easy read questionnaire to collect health details or for health action planning
8	<i>Make public health information accessible</i>	Adapted online easy read public health resources could be useful for people with learning disabilities. These could be printed and handed to the person, posted, or emailed. It means no matter where you live the same easy reads are being used across country
9	<i>Support with other health services</i>	If people need to be seen by another health service after their check, they may still need accessible information about this and they might still need support to access that service successfully

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10	<i>Have a designated accessibility champion</i>	To help all practice staff, have a dedicated member of the team who keeps up to date with information about working with and caring for people with learning disabilities. They should link to a regional lead person who shares good practice and training opportunities
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3 201 *Theme 1: Prioritisation*  
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6 202 This theme describes the rationale and different ways in which people with learning disabilities  
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8 203 should/could be prioritized in primary care with regards to access, health needs, and eligibility  
9  
10 204 for annual health checks. Examples included being prioritized on arrival and not being kept  
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12 205 waiting with participants valuing being seen promptly ‘sometimes the GP will see my daughter  
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14 206 on time, this has happened more recently as I’ve explained about my daughter’s inability to  
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16 207 wait and her anxiety’ (relative). Participants said ‘you don’t know how long they (the GP) are  
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18 208 going to be (it’s not always 5-minutes) then you get flustered because the doctor wasn’t on  
19  
20 209 time’. The waiting room environment may put people off attending, one participant saying:  
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24 210 *He doesn’t like to go because of how busy it can get...loads of noises... distractions...he*  
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26 211 *has anxiety...if he’s making noises and he’s aware of people looking at him (SHM)*  
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29 212 The theme highlights the importance of developing cultures within primary care that foster  
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31 213 supportive practice and prioritizing healthcare of people with learning disabilities (TR2).  
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33 214 Prioritisation comprised two subthemes: co-morbidity/mortality and accurate identification.  
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37 215 *Subtheme 1. Co-morbidity/mortality:* the rationale for prioritizing people with learning  
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39 216 disabilities was their susceptibility to health inequalities plus high co-morbidity and mortality  
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41 217 relative to the general population: ‘We have patients already at high risk of avoidable illness  
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43 218 and preventable mortality, have then another long-term condition to manage which is really  
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45 219 difficult and puts them at higher risk of death’.

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49 220 *It’s really important to develop that culture in the practice that if any of the people on*  
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51 221 *this {learning disability} list are ringing for help they go to the top of the queue. So that’s*  
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53 222 *part of the culture that we’re trying to develop in our practice to minimize the risk of stuff*  
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55 223 *being missed*  
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224 Another example of prioritizing was allocating time/resources; participants described offering  
225 double/longer-appointments to patients with learning disabilities who often have multiple  
226 conditions (TR5) and allowing enough time for health checks which vary in quality:

227 *People who are enthusiastic [about annual health checks] and see their value do them*  
228 *more thoroughly...some people will just put a few biometric results into a template...a*  
229 *health check needs to be a multisystem review, taking into context biological,*  
230 *psychological, sociological circumstances and needs to act on what it finds.*

231 *Subtheme 2. Accurate identification (TR3):* practices need to know which patients have a  
232 learning disability in order to identify them as being eligible/prioritised for health checks. This  
233 relies on correct read/diagnostic codes: ‘If you don’t have the right code you don’t get the  
234 health-care support’. Methods of identification described by participants included correct  
235 coding/registers, screening, and multi-agency working: ‘We need to work together, general  
236 practice, paediatrics and hostels’. Data pertaining to screening/inclusion tools is reported  
237 elsewhere (McKenzie et al., in review).

238 *Theme 2: Proactivity (TR4)*

239 A recurring theme described by participants was the importance of reaching-out to people with  
240 learning disabilities to encourage primary care attendance: ‘we know people with learning  
241 disability have premature/avoidable mortality, the only way we are can do something about  
242 that is to proactively identify them and bring them in’. The theme comprised two subthemes:  
243 reaching-out and innovation/improvement via monitoring, sharing good practice, and  
244 leadership.

245 *Subtheme 1: Reaching-out:* The reasons participants described it was important for primary  
246 care to reach-out to people with learning disabilities included that people may (i) be unaware  
247 of services e.g. health check entitlement (ii) be afraid (iii) feel they don’t need to attend. For

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3 248 example, while participants described seeing the value of health checks e.g. ‘they are important  
4  
5 249 and can tell you if things are getting worse’ and ‘there’s no reason I wouldn’t want one’, one  
6  
7  
8 250 participant with learning disabilities said there was ‘no sign saying you are allowed to have a  
9  
10 251 health check, I didn’t know I could get one’ and a relative said ‘health checks have been hit-  
11  
12 252 and-miss’. Further a sheltered housing manager reported that ‘sometimes the people we support  
13  
14  
15 253 don’t really know what an annual health check is’.

16  
17  
18 254 Proactive reaching-out was viewed to be important as people with learning disabilities and  
19  
20 255 carers may not understand the gravity/meaning of symptoms experienced: ‘It’s hard to know if  
21  
22 256 there are health issues particularly when my son presents with a high pain threshold and is non-  
23  
24  
25 257 speaking/unable to communicate pain/feelings’ (relative). A GP said ‘unless we provide  
26  
27 258 proactive healthcare to people that otherwise might not present typically we risk their health’.  
28  
29 259 Participants also said that ‘people decline them [health checks] and we have to chase around  
30  
31 260 for them’; reasons for this included ‘fear of health professionals/settings from past experiences’  
32  
33  
34 261 (relative) or feeling they don’t need a health assessment and have no-one to advocate for them:

35  
36  
37 262 *If a person is living independently they may feel they don’t want to bother the GP... a lot*  
38  
39 263 *of people with mild learning disabilities tend not to go to the GP so things can be missed*  
40  
41 264 *(SHM)*

42  
43  
44 265 Methods of reaching-out described by participants included extra phone calls/texts, offering  
45  
46 266 flexibility, information/invitations to attend in different formats, follow-up of non-  
47  
48 267 attenders/those not supported to come to an appointment, and assisting with implementation of  
49  
50 268 follow-up/secondary care arising from primary care visits (TR2 & TR9). Participants described  
51  
52  
53 269 how important reaching-out was for people without an advocate: ‘If people don’t have wrap-  
54  
55  
56 270 around support they probably fall through the cracks’ (SHM).  
57  
58  
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3 271 *Sub-theme 2: Innovation/improvement:* This included upskilling/supporting less experienced  
4  
5 272 practices via training/awareness raising, sometimes using a strategic/organisational level  
6  
7  
8 273 approach or facilitated by a learning disability lead (TR10):  
9

10 274 *There was a strategic approach from our CCG to share data monthly about how each*  
11  
12 275 *practice network was doing with annual health checks, whether they were on target/or*  
13  
14 276 *not; there was help to practices with poorer uptake.*  
15  
16  
17

18 277 Participants described how sharing good practice improves quality: ‘there are various  
19  
20 278 suboptimal [annual health check] templates being used; our CCG has been proactive ensuring  
21  
22 279 everybody uses the national template...we demonstrated how to do annual health checks using  
23  
24 280 the template’. One participant described the importance of a named person supporting strategy  
25  
26 281 implementation e.g. reaching targets: ‘I’m the lead for learning disability...so it’s my  
27  
28 282 responsibility to make sure they’re all done [health checks]’.  
29  
30  
31

32 283 Participants described how training can improve skills in primary care: ‘people on reception  
33  
34 284 don’t give you enough time, they rush you and you can make mistakes...if they know you have  
35  
36 285 a learning disability they can talk to you in a different way’ and ‘receptionists should have  
37  
38 286 training to understand challenging behaviour’ (relative). A GP commented that ‘education of  
39  
40 287 staff is really important so they are aware these patients might be phoning up’. However,  
41  
42 288 training may require co-ordination/facilitation: ‘the practice could have a designated lead that  
43  
44 289 everybody recognises as the learning disability doctor/nurse’ (practice nurse) (TR10).  
45  
46  
47  
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49

50 290 *Theme 3. Personalisation (TR2 & TR5)*  
51

52 291 Participants described the importance of offering a bespoke/personalised service to people with  
53  
54 292 learning disabilities to address some of the things that can make access to primary care difficult.  
55  
56 293 It was viewed as important for a clinician/or reception to know/be on first-name terms with  
57  
58 294 patients with learning disabilities for continuity of care: ‘I know the nurses quite well and that’s  
59  
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1  
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3 295 helpful' and 'seeing the same GP so they get to know you a bit'. Sub-themes included primary  
4  
5 296 care interface problems and reasonable adjustments.  
6  
7

8  
9 297 *Sub-theme 1. Primary care interface problems:* It was evident across all stakeholders that  
10  
11 298 aspects of the primary care interface were challenging/inaccessible to people with learning  
12  
13 299 disabilities e.g. the automated telephone response options when calling the surgery:  
14  
15

16 300 *A patient ringing up with a mild learning disability, might not be able to wait in a phone*  
17  
18 301 *queue, might struggle with phone numbers...if it says press '1'. Those things haven't been*  
19  
20 302 *thought about for people with learning disabilities*  
21  
22

23 303 One participant with a learning disability said they: 'might not be able to use the check-in  
24  
25 304 machine and put in a date of birth'; ensuring carers/family members have consent to  
26  
27 305 access/make appointments may help. A GP described how:  
28  
29

30 306 *We only book four weeks ahead, if I say I need to see you in six-weeks, they can't book*  
31  
32 307 *that appointment, so we'll say you need to ring closer to the time; someone who hasn't*  
33  
34 308 *got a carer, they're probably not going to remember*  
35  
36  
37

38 309 *Sub-theme 2. Reasonable adjustments:* One relative suggested 'ask if the patient needs any  
39  
40 310 reasonable adjustments; what would make the visit easier'. This theme included booking  
41  
42 311 appointments at times that suit the person with learning disabilities and carer/support staff so  
43  
44 312 they could attend with them: 'they could talk for me if I didn't know the answer'. Participants  
45  
46 313 described a lot of people wanting a support person with them however, direct communication  
47  
48 314 from the GP/nurse was viewed important, one participant saying: 'It's important to speak to  
49  
50 315 the person; it's not nice to be talked over the top of' (TR6).  
51  
52  
53

54 316 Other examples were provision of accessible information; one participant with learning  
55  
56 317 disabilities suggested avoiding jargon for example: 'They should be called *yearly health*  
57  
58 318 *checks...yearly is clearer than annual*' (TR1). Other suggestions were providing information  
59  
60

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3 319 beforehand: 'Some people might be frightened' so 'letting people know what to expect at their  
4  
5 320 appointment makes it less scary'. Clear information before/during the appointment and picture-  
6  
7 321 questionnaires were found helpful by people with learning disabilities: 'I liked that I could  
8  
9 322 watch on You-tube what a health check is' and 'you can fill in a form e.g. if you're afraid of  
10  
11 323 needles' (TR7). One participant described receiving a postal questionnaire 'I filled it in with  
12  
13 324 help from my support worker'; people with learning disabilities and GPs/practice nurses  
14  
15 325 reported completing a questionnaire in advance helped prepare for the appointment.  
16  
17  
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19

20 326 Other pre-annual health check preparations described by participants included texts, videos,  
21  
22 327 picture-questionnaires and phone calls to promote the check and asking when/how it would  
23  
24 328 work best for patients with learning disabilities e.g. was there a particular person they would  
25  
26 329 like to attend with them. A GP described how offering flexibility around health checks  
27  
28 330 improved uptake: 'We went from 49% uptake of annual health checks to 98%'.  
29  
30  
31

32 331 However, limitations in reasonable adjustments provision were evident across stakeholders:  
33  
34 332 'I'm rolling out the idea of it being coded that patients need a reasonable adjustment...when I  
35  
36 333 talk to practices they're not really doing it; it's in their heads but they're not making it visible'.  
37  
38 334 One GP described how staff may lack awareness: 'I think we need to talk about reasonable  
39  
40 335 adjustments in a more accessible way, even for professionals...they've got reasonable  
41  
42 336 adjustments written on their notes that assumes that our staff know what reasonable  
43  
44 337 adjustments are'.  
45  
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47  
48

#### 49 338 **Theme 4: Prevention**

50  
51 339 This theme related to healthy lifestyles and supporting access to follow-up/secondary care.  
52  
53 340 *Subtheme 1: Healthy lifestyles:* Participants described the role of primary care supporting  
54  
55 341 people with learning disability accessing public health campaigns/interventions and healthy  
56  
57  
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3 342 behaviour/choices e.g. diet/exercise (TR2). Participants described how availability of easy-read  
4  
5 343 public health information can be a valuable resource for prevention:  
6  
7

8 344 *To understand that making health choices around food is really important...people*  
9  
10 345 *without a learning disability struggle on that...people with a learning disability end-up*  
11  
12 346 *with diabetes and struggle to manage it (TR 8 & 9)*  
13  
14

15 347 While some public health information was found available in accessible formats participants  
16  
17 348 described some gaps and/or comments indicated a lack of awareness of available resources:  
18  
19

20 349 *It would be really helpful to have a website that has all the common health conditions*  
21  
22 350 *e.g. if you've got asthma I can print something off...there's a lot of medical terminology*  
23  
24 351 *in the leaflets we give people (TR8)*  
25  
26  
27

28 352 *Subtheme 2: Supporting access to secondary care:* This related to problems with follow-up  
29  
30 353 after health checks including for people who find it hard to reach/or are not brought to the  
31  
32 354 service: *'some people may need a named individual to support them booking appointments or*  
33  
34 355 *accessing test results and follow-up appointments'* (relative) and *'sometimes they rely on*  
35  
36 356 *carers to remind them that they have follow-up, I don't necessarily think they would remember'*  
37  
38 357 (sheltered housing manager).  
39  
40  
41

42 358 Facilitating support for follow-up care was viewed as crucial, and may include referral into  
43  
44 359 other services to support patients better e.g. care co-ordination: *'It's thinking about practical*  
45  
46 360 *safety nets for this person that will allow them not to become lost to follow-up'* (TR9).  
47  
48

49 361 Participants also described the importance of accessible health action plans that are shared with  
50  
51 362 relevant allied health professional to facilitate follow-up (TR9).  
52

53 363 *So often there can be identification of a symptom that needs further exploration, then*  
54  
55 364 *investigations and review and even for somebody without a learning disability that can*  
56  
57 365 *be quite complex*  
58  
59  
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3 366 *(Figure 2 around here)*  
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5

6 367 **Discussion**  
7

8 368 Four interconnected over-arching themes were identified describing approaches to improve  
9  
10 369 primary care access for people with learning disabilities; the themes map onto dimensions of  
11  
12 370 service provision informing different aspects of primary care and development of ten accessible  
13  
14 371 recommendations. Aligned with previous research, participants emphasized prioritizing people  
15  
16 372 with learning disability in primary care given high prevalence of multiple chronic health  
17  
18 373 conditions, vulnerabilities and mortality.<sup>5</sup> However, participants also described challenges to  
19  
20 374 prioritisation. In common with previous research people were not always correctly coded; GPs  
21  
22 375 being unaware a person has a learning disability is a barrier to implementing appropriate  
23  
24 376 support/adjustments and systems for addressing this require development.<sup>5 12</sup> Prioritisation  
25  
26 377 maps onto to several aspects of service provision – data/coding systems, training and strategy;  
27  
28 378 a strategic proactive approach by a learning disability lead maybe required to instigate/drive  
29  
30 379 systems-level changes e.g. training to facilitate prioritisation.<sup>25</sup> Previous research highlighted  
31  
32 380 training as effective in reducing barriers to primary care for people with learning disabilities.  
33  
34 381 <sup>17</sup> Important areas for training described in our study included identification of people who may  
35  
36 382 not be coded/be incorrectly coded, definitions of/what constitutes reasonable adjustments, and  
37  
38 383 national guidance initiatives. For example, while there is a national health check template it  
39  
40 384 was evident that it is not always utilised; training was seen to facilitate improvement e.g. greater  
41  
42 385 health check uptake.

43  
44 386 Previous research highlighted the importance of health checks for preventing treatable  
45  
46 387 conditions being missed;<sup>9 10</sup> and a theme identified in our study was prevention. Initiatives that  
47  
48 388 increased uptake of annual health checks included data collection/sharing, targeted support for  
49  
50 389 practices with poor uptake, methods of identifying people who may be incorrectly coded,  
51  
52 390 proactively reaching-out to patients and offering flexibility. In accordance with research to  
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3 391 improve comprehensibility of health questionnaires<sup>18</sup> participants valued accessible  
4  
5 392 information received before/during primary healthcare appointments e.g. picture  
6  
7  
8 393 questionnaires especially if people are afraid of attending.<sup>21</sup> Previous research highlighted  
9  
10 394 accessible information is not always available however and needs to be individualised;<sup>14 15</sup> this  
11  
12 395 was reflected in our third theme of personalisation. Participants viewed it important to consider  
13  
14 396 accessibility in broader contexts e.g. embedding relevant Easy-read information into long-term  
15  
16 397 condition management templates and health checks. Participants agreed accessibility of health  
17  
18 398 prevention/public health information/resources, follow-up and secondary care/hospital  
19  
20 399 admissions also require consideration. This requires a primary care culture supportive of people  
21  
22 400 with learning disabilities, and proactive service provision responsive to hard-to-reach patients,  
23  
24 401 that can bridge agencies/providers e.g. a learning disability nurse to liaise with  
25  
26 402 secondary/tertiary care.

30  
31  
32 403 Aligned with previous research promoting a more active role for people with learning  
33  
34 404 disabilities in healthcare interactions,<sup>24</sup> participants valued communication directed to the  
35  
36 405 person with learning disability when attending with a supporter. In accordance with previous  
37  
38 406 research it was evident from participants that there were significant barriers across  
39  
40 407 services/systems e.g. barriers to implementation of preventative healthcare<sup>22</sup> and a strategic  
41  
42 408 approach is important to address these; aligned with national guidance a regional learning  
43  
44 409 disability lead can facilitate strategic approaches across practices<sup>25</sup> and this was seen as  
45  
46 410 important by participants (TR10). Designated champions within practices linked to a regional  
47  
48 411 learning disability lead can facilitate ensuring the right support, adjustments and liaison is  
49  
50 412 offered to support people with learning disabilities and families.

51  
52  
53 413 A strength of the study is exploring views of three stakeholder groups and using information  
54  
55 414 gathered to build on previous research and develop/co-produce accessible recommendations  
56  
57 415 informed by stakeholder consultation. While data collection was regional, we believe the



1  
2  
3 416 findings will have national and international relevance. A regional inner-city GP practice  
4  
5 417 affirmed utility of the recommendations (saying all seemed practical/could be implemented  
6  
7 418 within practice); and indicated the key to change was a named practice-lead, linked through  
8  
9 419 local primary care networks who could then implement the other recommendations. Future  
10  
11 420 research could explore implementation of the recommendations, and standardised  
12  
13 421 methods/processes of identifying/coding reasonable adjustments.  
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30

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33  
34 438 Investigator. All authors contributed to conceptualisation and development of data collection  
35  
36 439 materials. SW & JB collected data. SW and SH wrote the first draft of the manuscript. All  
37  
38 440 authors contributed during the editing and reviewing process. All authors approved the final  
39  
40 441 manuscript.  
41  
42

43  
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45  
46 443 opinion (Reference: 2102).  
47  
48

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50  
51 445 they contain information that could compromise the privacy of research participants. Some  
52  
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56  
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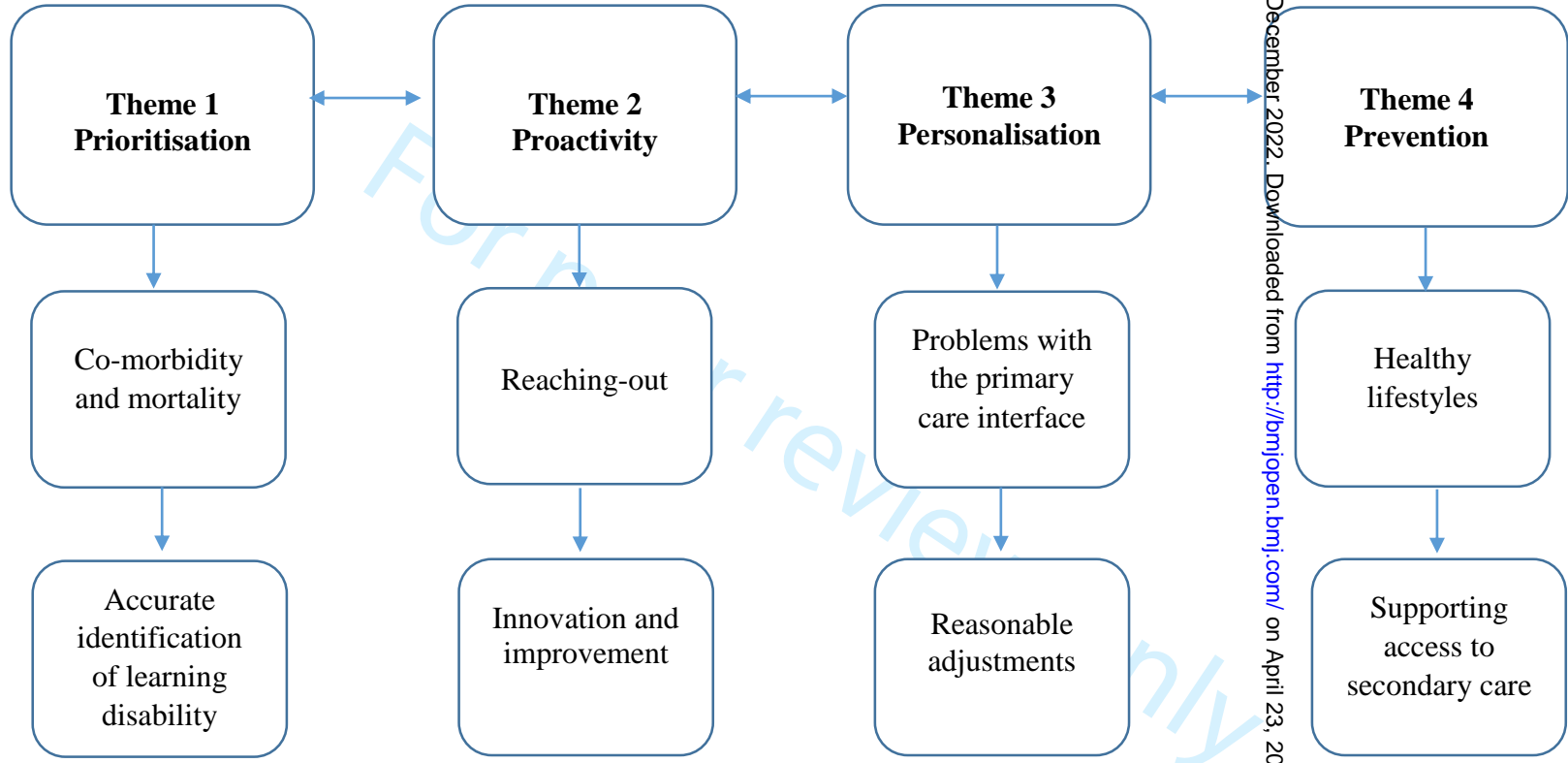


Figure 1 Structure of themes and subthemes

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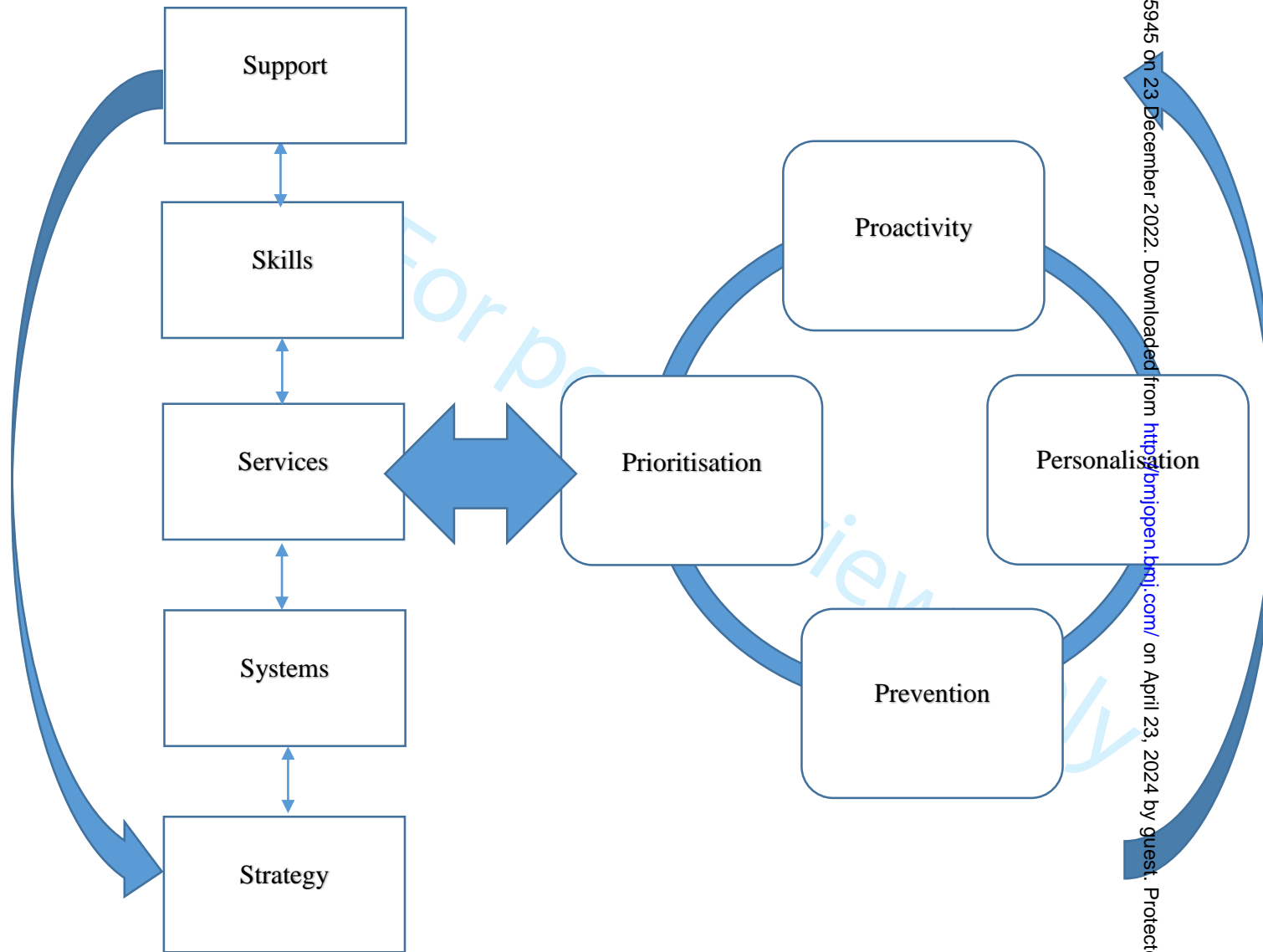


Figure 2 The four themes and their application to different aspects of primary care service provision

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3 *Online Supplementary Materials (OS) 1.*  
4

5 Focus group/interview topic schedule for people with learning disabilities and relatives

6  
7 At the focus groups, we will talk about health checks. By health checks, we mean going to  
8  
9 the doctors or GPs each year to talk about your health and to have some checks done. “It’s  
10  
11 like a full MOT for the body, to check if you are healthy.”  
12

13  
14  
15 We will ask the following questions in the focus group

16 Thank you for agreeing to take part in our focus group

17  
18 What things make it difficult for people with learning disabilities to go to the GP?

19  
20 What things make it easier for people with learning disabilities to go to the GP?

21  
22 What training should people working at the GPs have? (E.g. receptionists)

23  
24 What do people think of health checks? Are they important?

25  
26 One thing that stops people getting the best health care is that others do not know they have a  
27  
28 learning disability.

29  
30 What if someone had a learning disability but the GP didn’t know about it?

31  
32 We are thinking a questionnaire might be good to help with this

33  
34 1. What do you think the good things would be about using a questionnaire to help the GP  
35  
36 know if someone had a learning disability? (For example, finding out they had a learning  
37  
38 disability, others understanding more about them)

39  
40 2. What do you think are the main bad things? (For example feeling embarrassed/shocked to  
41  
42 find out)

43  
44 Suggestions...

45  
46 Complete the following sentence... Health checks are ...

- 47 • Important
- 48 • Necessary
- 49 • A waste of time
- 50 • Good thing if you’re offered them

51  
52 How have people found health checks/ what are people’s expectations and experiences of  
53  
54 health checks?

55  
56 Is there anything that you would like to improve about having your/ your relative’s health  
57  
58 check?

59  
60 Any other comments?

How can access to the GPs for people with severe/profound learning disabilities, be  
improved? (*Relatives*)

1  
2  
3 Can you think of any reasons why you/ your relative would not want a health check?  
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3 *Online Supplementary Materials (OS) 2. Interview Schedule for GPs, nurse practitioners and*  
4 *sheltered housing managers*  
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8 Part 1. Annual Health checks  
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- In your view, how are annual health checks for people with learning disability working at the moment? Do the health checks take place on an annual basis?
  - What systems do you have in place that alerts you to an annual health check being due to be carried out?
  - When someone new joins the surgery does their record automatically flag if they have a learning disability and need an annual health check?
  - Do some people decline a health check? If so, why?

26 Part 2. Learning disability inclusion tool – *reported elsewhere*  
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29 Part 3 A. Barriers to people with learning disability accessing primary care  
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- In your view what are the main barriers to people with learning disability accessing primary care?
  - What do you think are the main environmental barriers?
  - What do you think are the main social barriers? (e.g. attitudinal issues, communication issues, phobias, prejudice)
  - What things in your surgery or systems make it difficult for people with learning disability to get their annual health check?
  - What improvements could be made within NHS systems to help people with learning disability have regular health checks?

52 2. What are the barriers to follow-up after primary care and implementation of a health plan?  
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54 Part 4. Reasonable adjustments  
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- What things in your surgery or systems work well for people with learning disabilities getting their annual health check, and what could be improved?

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3 • What reasonable adjustments facilitate people with learning disability accessing  
4 primary care?  
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8 Part 5. COVID-19  
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- 10 • What mitigation is required to be in place in primary care settings for people with  
11 learning disability in the context of COVID-19?  
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13 • In respect of health checks for people with learning disabilities what have you learned  
14 from COVID-19?  
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16 • What changes would you incorporate going forwards?  
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18 • Is there someone within the surgery provision that could set up or audit people's  
19 capacities for phone and online appointments?  
20  
21 • How can people with learning disabilities be supported to accessing the GP more often  
22 during COVID-19?  
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# BMJ Open

## Improving access to primary care and annual health checks for people who have a learning disability. A multi-stakeholder qualitative study

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Improving access to primary care and annual health checks for people who have a learning disability. A multi-stakeholder qualitative study

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## Abstract

Objectives: To investigate key stakeholders' views on how to improve access to primary care in general practice settings for people with learning disabilities (or intellectual disabilities). Further to explore how inequalities and barriers in specific areas including annual health checks might be addressed.

*Design:* A qualitative study design was utilized with data collected during focus groups, interviews and open-response surveys; data analysis was thematic and informed by stakeholder consultation. Processes to facilitate quality included triangulation of stakeholder perspectives, triangulation of data collection methods, and checking interpretation of findings with participants.

*Setting:* UK regional services including learning disability organisations, primary care general practitioner clinical practice networks and supported housing organisations.

*Participants:* Sixteen people participated in the study: 4 people with learning disabilities participated in a focus group; 4 relatives completed an interview or survey; 8 GPs, practice nurses and supported housing managers participated in interviews.

*Results:* Five overarching themes describing approaches to improve primary care access for people with learning disabilities were identified including: prioritisation, proactivity, innovation and improvement, personalisation and prevention and follow-up. Definitions of themes were described and illustrated with quotes. Ten recommendations informed by the thematic analysis, stakeholder consultation, research and primary care guidance were co-developed with people with learning disabilities.

*Conclusions:* All stakeholders identified problems, with primary care interfaces being misaligned with the needs of people with learning disabilities. The recommendations informed by all stakeholders can be used to guide development of service provision to better meet the

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3 needs of people with learning disabilities in primary care. Future research should explore  
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5 professionals' understanding of reasonable adjustments.  
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3 **Article Summary:** *Strengths and limitations of this study*  
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- 6 • Qualitative data were collected from 16 key stakeholders (people with learning  
7 disabilities, relatives, general practitioners, practice nurses and sheltered housing  
8 managers) on ways to improve primary care access for people with learning disabilities.  
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  - 10 • Stakeholder consultation informed study design and interpretation of research findings  
11 and recommendations were co-developed with people with learning disabilities.  
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  - 13 • We used convenience sampling and the number of participants was small though this  
14 is appropriate for qualitative designs.  
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  - 16 • Different methods of data collection were utilized, perspectives were triangulated  
17 across key stakeholders and interpretation of the research findings was checked with  
18 research participants.  
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31 Keywords: primary care; learning disabilities, health checks, health inequalities  
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35 **Word Count:** 4070  
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## Introduction

People with learning disabilities experience higher burden of chronic disease and were at increased risk of hospitalization and mortality during the COVID-19 pandemic compared to the general population.<sup>1-3 4</sup> Given health vulnerabilities, prioritizing the health needs of people with learning disabilities is crucial.<sup>5</sup> Guidance addressing this includes standards of care published in Canada;<sup>6 7</sup> and United Kingdom (UK) recommendations encompass annual health checks, learning disability registers, reasonable adjustments, and champions to share good practice.<sup>8-10</sup>

Annual health checks can uncover previously unknown conditions,<sup>11</sup> reduce preventable emergency hospitalizations,<sup>12</sup> allow monitoring treatments and foster continuity of care.<sup>7</sup>

Annual health checks are structured assessments conducted by General Practitioners (GPs) and practice nurses who facilitate access for people with learning disabilities into healthcare services.<sup>13</sup>

Learning disability registers, and diagnostic codes for clinical terms ('READ' or SNOMED [Systematized Nomenclature of Medicine] codes) used in the UK NHS facilitate identifying people attending primary care who may have a learning disability (NHS Digital). However, people may be un-coded or incorrectly coded; without correct coding for learning disability they can not gain access to appropriate healthcare and adjustments. Methods of identifying people with learning disabilities in primary care are required.<sup>14 15</sup>

Despite initiatives and financial incentivisation for annual health checks,<sup>16</sup> barriers in primary healthcare persist for people with learning disabilities. Examples include low uptake of health checks,<sup>17</sup> and women with learning disabilities being less likely than those without to have cervical cancer screening or physiotherapy.<sup>18 19</sup> Further, while prevalence of long-term conditions in primary care (e.g. diabetes), is higher among people with learning disabilities,

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3 best-practice condition-management indicators are lower relative to the general population.<sup>20</sup>

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5 In a study examining barriers to improving primary care for people with learning disabilities  
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7 in Canada, services in which leadership only passively supported innovation were less likely  
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9 to implement care improvements.<sup>21</sup>

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13 Other barriers in primary care for people with learning disabilities, include fear, carer  
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15 unawareness of health problems,<sup>22</sup> and lack of evidence-based lifestyle interventions (e.g.  
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17 obesity prevention).<sup>23</sup> People with learning disabilities may lack assertiveness, communication  
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19 skills, and carers to support primary care attendance, and have difficulties self-managing health  
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21 needs.<sup>24 22 25 17</sup> In the United States, adults with learning disabilities living unsupported had  
22  
23 more emergency hospital visits compared with other residency types.<sup>26</sup> Reviews of service  
24  
25 user and carer perspectives on barriers to accessing primary care, identified time, knowledge,  
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27 awareness, training, communication, embarrassment and active involvement in healthcare  
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29 decision-making as factors.<sup>24 27</sup>

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35 Access to primary care for people with learning disabilities can be facilitated by individualised  
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37 easy-read information,<sup>28 29</sup> health questionnaires,<sup>30</sup> longer appointments,<sup>17</sup> assisting those  
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39 living unsupported,<sup>26</sup> and having a proactive,<sup>7</sup> flexible approach to suit the person.<sup>31</sup>  
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41 Practitioner and direct support staff training can also reduce barriers.<sup>32 33 34</sup> Practitioners may  
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43 lack confidence working with people with learning disabilities,<sup>35</sup> and experiential learning was  
44  
45 found beneficial for physicians in Canada.<sup>36</sup>

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50 While research into primary care for people with learning disabilities is growing, co-produced  
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52 research across different stakeholders is sparse. This study aimed to elicit key stakeholder  
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54 views on ways to improve GP primary care access for people with learning disabilities, and co-  
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56 produce recommendations.

## 57 58 59 60 **Methods**

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3 The study was qualitative. Data were collected during focus groups, interviews and surveys,  
4 from June-December 2021 by the first and second authors. Analysis was thematic with an  
5 inductive experiential framework informed by stakeholder consultation. Newcastle University  
6 Research Ethics Committee provided ethical approval (Ref: 2102/10380/2020).  
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### 11 *Participants*

12 Recruitment was purposive to capture a range of stakeholder perspectives. Inclusion criteria  
13 were adults (>18 years of age) with mild to moderate learning disabilities, defined as having  
14 capacity to consent to participate in the research. People with learning disabilities were  
15 recruited via a UK regional charity who distributed accessible study information to people with  
16 learning disabilities and informed the research team of those meeting inclusion criteria and  
17 interested in participating. Prior to meeting the researcher accessible study information was  
18 read with people with learning disabilities by an advocate. Following this the information was  
19 read with people with learning disabilities by the first author who also asked questions about  
20 the information to assess understanding and capacity to informed consent. Relatives of adults  
21 with learning disabilities were recruited via a regional charity and contacts network who  
22 distributed study information and researcher details.  
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40 GPs, practice nurses and sheltered housing managers were recruited through regional clinical  
41 and practitioner networks.  
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### 45 *Data collection*

46 Online data were collected using Microsoft Teams after completion of informed consent. An  
47 online focus group was conducted with people with learning disabilities and supported by an  
48 advocate who facilitated online access. Data collection from relatives was by online interview  
49 or survey depending on their preference. The survey comprised the same open-response  
50 questions as the interview schedule. During focus groups and interviews, prompts were used  
51 to elicit detail, for example: can you tell me more about that? Key points from the focus group  
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3 with people with learning disabilities were summarized by the researcher and read back to the  
4 group to check accuracy. Interviews with relatives were audio-recorded and transcribed. The  
5 focus groups, interview and survey topic schedules are shown in the Online Supplementary  
6 materials (OS1).  
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13 Online semi-structured interviews conducted with GPs, nurse practitioners and sheltered  
14 housing managers were audio-recorded and transcribed. The interview schedule (OS2)  
15 comprised five sections: annual health checks, learning disability inclusion tools, barriers  
16 accessing primary care, reasonable adjustments and COVID-19. Data on inclusion tools is  
17 reported elsewhere (McKenzie et al., in review). All participants were sent a debrief email.  
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### 26 *Patient and Public Involvement*

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28 Study documents (consent, information sheets, focus group topic guides) were developed in  
29 consultation with a research advisory group led by people with learning disabilities. Feedback  
30 included to add content, edit wording, and create a debrief document. GPs were consulted  
31 regarding the interview topic schedule, and advised on wording and content. Initial review of  
32 data indicated living arrangements impact primary care access; this was discussed with a GP  
33 and informed our decision to recruit sheltered housing managers. An online presentation of  
34 preliminary findings was made to a research advisory group led by people with learning  
35 disabilities. Study findings were presented to a GP practice meeting.  
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### 47 *Analysis*

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49 Thematic analysis was conducted manually by the first and last authors (an experienced  
50 clinician and researcher in the field of learning disabilities) in iterative phases following  
51 anonymization: (1) data familiarisation (2) coding (3) developing a coding framework (4)  
52 identifying themes (5) reviewing, revising and confirming themes and definitions (6) and  
53 identifying illustrative quotes.<sup>37 38</sup> Informed by thematic analysis findings, research, primary  
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3 care guidance and consultation with key stakeholders, recommendations were co-produced  
4 with people with learning disabilities (Table 1). In accordance with qualitative analysis best-  
5 practice, trustworthiness was ensured by: checking interpretation of findings with participants,  
6 triangulating perspectives and important aspects of the topic by collecting data from different  
7 stakeholders using different methods, and by inviting participants to comment on a summary  
8 of findings.<sup>37 38</sup>

## 17 **Results**

19 Sixteen people participated comprising 4 people with learning disabilities (1 male; 3 female);  
20 four relatives (all female); and eight GPs, practice nurses and supported housing managers (7  
21 female; 1 male). GPs, practice nurses, supported housing managers and one relative completed  
22 interviews, four people with learning disabilities took part in a focus group, and three relatives  
23 completed surveys. Five themes with subthemes were identified from the focus group,  
24 interviews and survey data: prioritisation, proactivity, innovation and improvement,  
25 personalisation, prevention and follow-up (Figure 1).

26 At the time of the study primary care services were still under considerable pressure from the  
27 impact of COVID-19, and participants described changes to healthcare delivery including use  
28 of virtual technology: *'there was lots of Facetime consultation'* (sheltered housing manager:  
29 SHM) and *'we had to put them (health checks) all on hold'* (GP). Some changes worked well  
30 and were adopted longer-term: *'Now we've got the technology in place, it allows patient  
31 choice if somebody finds it more comfortable with consultation by video or phone'*. However,  
32 this wasn't always suitable: *'There are bits of health checks that need to be done face-to-face;  
33 you can't do a breast or testicle check over the phone or video'*.

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*(Figure 1 here)*

### *Theme 1: Prioritisation*

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3 This theme described the rationale for prioritizing people with learning disabilities in primary  
4 care, and how to support this (Recommendation: R2), and comprised three subthemes: spaces  
5 for people with different needs, co-morbidity, mortality and accurate identification.  
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11 *Subtheme 1: Spaces for people with different needs*

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13 Participants indicated that waiting rooms may put people off attending and suggested the  
14 benefits of spaces for people with learning disabilities: *'He doesn't like to go because of how*  
15 *busy it can get...loads of noises... distractions...he has anxiety...if he's making noises and he's*  
16 *aware of people looking at him' (SHM)*. Participants also valued being seen promptly  
17 *'sometimes the GP will see my daughter on time, this has happened more recently as I've*  
18 *explained my daughter's inability to wait and her anxiety' (relative)*. A participant with a  
19 learning disability said *'you don't know how long they (the GP) are going to be, it's not always*  
20 *5-minutes, then you get flustered because the doctor wasn't on time'*.  
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33 *Subtheme 2. Co-morbidity and mortality*

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35 Given prevalence of multiple health conditions and high mortality among people with learning  
36 disabilities relative to the general population, participants said unless they are prioritised health  
37 conditions may be missed: *'If any of the people on this [learning disability] list, ring*  
38 *for help, they go to the top of the queue. So that's the culture we're trying to develop in our*  
39 *practice, to minimize the risk of stuff being missed' (GP)*.  
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47 Primary care checks were viewed key to identifying preventable health conditions, and  
48 important as people with learning disabilities may find it difficult to manage multiple-health  
49 conditions: *'We have patients at high risk of avoidable illness and preventable mortality, have*  
50 *another long-term condition to manage, which is really difficult and puts them at higher risk*  
51 *of death' (GP)*.  
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3 Prioritization required allocating resources; participants described offering longer  
4 appointments and allowing enough time for thorough health checks for patients with learning  
5 disabilities (R5): *'People who are enthusiastic [about annual health checks] and see their value,*  
6 *do them more thoroughly. Some people will just put a few biometric results into a template...a*  
7 *health check needs to be a multi-system review, taking into context biological, psychological,*  
8 *sociological circumstances and needs to act on what it finds' (GP).*  
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#### 17 18 *Theme 2: Proactivity (R4)*

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20 A recurring theme described by participants was the importance of proactively encouraging  
21 people with learning disabilities to attend primary care. The theme comprised two subthemes:  
22 accurate identification and reaching-out.  
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#### 28 *Subtheme 1. Accurate identification (R3)*

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30 In order to prioritise people, practices need to know which patients have a learning disability:  
31 *'we know people with learning disabilities have premature avoidable mortality. The only way*  
32 *we can do something about that is to proactively identify them and bring them in' (GP).*  
33  
34 Identification of patients with learning disabilities required the correct diagnostic codes, use of  
35 registers, screening, and multi-agency working: *'We need to work together, general practice,*  
36 *paediatrics and hostels' because 'if you don't have the right code, you don't get the*  
37 *[appropriate] health-care' (GP).*  
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47 *Subtheme 2: Reaching-out:* Participants explained that it was important to reach-out to people  
48 with learning disabilities who may be unaware of health service entitlements. While  
49 participants with learning disabilities could see the value of health checks: *'they are important,*  
50 *and can tell you if things are getting worse' and 'there's no reason I wouldn't want one', one*  
51 *person with a learning disability said there was 'no sign saying you're allowed a health check,*  
52 *I didn't know I could get one'. A relative described inconsistent service provision: 'health*  
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3 *checks have been hit-and-miss*', while a sheltered housing manager said *'sometimes the people*  
4 *we support don't know what an annual health check is*'.

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9 Participants said that *'people decline them [health checks], and we have to chase around for*  
10 *them*' (GP). Reasons included *'fear of health professionals and settings from past experiences*  
11 (relative), or feeling they don't need a health assessment and have no-one to advocate for them:  
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13 *'If a person is living independently, they may feel they don't want to bother the GP... a lot of*  
14 *people with mild learning disabilities tend not to go to the GP so things can be missed*' (SHM).

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20 Participants described the importance of reaching-out to people without an advocate: *'If people*  
21 *don't have wrap-around support, they probably fall through the cracks*' (SHM).

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26 Participants highlighted that people with learning disabilities may have atypical symptoms, and  
27 they and carers may not understand symptom significance: *'It's hard to know if there's health*  
28 *issues, when my son is non-speaking and unable to communicate pain or feelings*' (relative). A  
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GP said *'unless we provide proactive healthcare to people that might not present typically, we*  
*risk their health*'. Methods of reaching-out included extra phone-calls, texts, offering  
flexibility, follow-up of non-attenders and those unsupported, and supporting follow-up  
healthcare arising from primary care visits (R4 & R9).

### *Theme 3: Innovation and improvement*

*Subtheme 1: Training.* Participants described how training improves primary care staff skills  
and awareness; a GP commented: *'education of staff is really important, so they're aware these*  
*patients might be phoning up*'. This was emphasized by a participant with a learning disability:  
*'people on reception don't give you enough time, they rush you and you can make mistakes...if*  
*they know you've a learning disability, they can talk to you in a different way*'. A relative  
suggested training on behaviours viewed as challenging would be helpful: *'receptionists should*  
*have training to understand*'.



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3 *Subtheme 2: Sharing good practice.* Participants described how sharing good practice can  
4 improve quality: *'there are various suboptimal [annual health check] templates being used.*  
5  
6 *Our CCG [clinical commissioning group] has been ensuring everybody uses the national*  
7 *template. We demonstrated how to do annual health checks using the template'* (GP). Sharing  
8 good practice also included supporting less experienced practices: *'there was a strategic*  
9 *approach from our CCG to share data monthly, about how each practice network was doing*  
10 *with annual health checks, whether they were on target or not. There was help to practices*  
11 *with poorer uptake'*. (GP)

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22 Participants described the importance of a named person supporting development and good  
23 practice: *'I'm the learning disability lead...so it's my responsibility to make sure they're all*  
24 *done [health checks]'* (R10) and *'the practice could have a designated lead, that everybody*  
25 *recognises as the learning disability doctor or nurse'* (practice nurse) (R10).

#### 26 27 28 29 30 31 32 *Theme 4. Personalisation (R2, R5)*

33  
34 A personalised service was valued, including for continuity of care, participants with learning  
35 disabilities said: *'I know the nurses quite well, that's helpful'* and *'seeing the same GP, so they*  
36 *get to know you a bit'*. Sub-themes included primary care interface problems and reasonable  
37 adjustments.  
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45 *Sub-theme 1. Primary care interface problems:* It was evident across all stakeholders that the  
46 primary care interface was challenging to people with learning disabilities, including  
47 automated telephone response options when phoning the surgery: *'A patient ringing-up with a*  
48 *mild learning disability, might not be able to wait in a phone queue, and struggle with phone*  
49 *numbers...if it says press '1'. Those things haven't been thought about for people with learning*  
50 *disabilities'* (GP). A participant with a learning disability said they: *'might not be able to use*  
51 *the check-in machine and put in a date of birth'*. A GP described how: *'We only book four*  
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3 *weeks ahead. If I say I need to see you in six-weeks, they can't book that appointment and need*  
4 *to ring closer to the time. Someone who hasn't got a carer, will probably not remember'.*  
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8 *Sub-theme 2. Reasonable adjustments:* A GP described how offering flexibility around health  
9 checks improved uptake: *'We went from 49% uptake of annual health checks to 98%'. A*  
10 *relative suggested 'ask if patients need any reasonable adjustments, and what would make the*  
11 *visit easier' (R2 and R5), for example booking appointments at times to suit the person with a*  
12 *learning disability and carer who could attend with them. A participant with a learning*  
13 *disability said: 'they could talk for me if I didn't know the answer'. However, direct*  
14 *communication from GPs or nurses was key, one participant with a learning disability saying:*  
15 *'It's important to speak to the person; it's not nice to be talked over the top of' (R6).*  
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27 Other examples were provision of accessible information and avoiding jargon (R7 and R8); a  
28 participant with a learning disability said: *'They should be called yearly health checks...yearly*  
29 *is clearer than annual' (R1). Clear information before and during appointments was found*  
30 *helpful by people with learning disabilities: 'Some people might be frightened' so 'letting*  
31 *people know what to expect at their appointment makes it less scary' and 'I liked that I could*  
32 *watch on You-tube what a health check is' (R7). A participant with a learning disability*  
33 *described receiving a postal picture-questionnaire and said: 'you can fill in a form, if you're*  
34 *afraid of needles' and 'I filled it in with help from my support worker'.*  
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46 Participants described gaps in awareness of accessible resources: *'It would be really helpful to*  
47 *have a website that has all the common health conditions. If you've got asthma I can print*  
48 *something off. There's a lot of medical terminology in leaflets we give people' (GP) (R7).*  
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53 Limitations in reasonable adjustments provision was evident, a GP said: *'I'm rolling out the*  
54 *idea of coding that patients need a reasonable adjustment. When I talk to practices they're not*  
55 *really doing it; it's in their heads but they're not making it visible'. A GP explained staff may*  
56 *lack awareness: 'I think we need to talk about reasonable adjustments in a more accessible*  
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3 way, even for professionals. They've got reasonable adjustments written on their notes; that  
4  
5 assumes our staff know what reasonable adjustments are'.  
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## 8 **Theme 5: Prevention and Follow-up healthcare**

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10 This theme focussed on supporting follow-up resulting from primary care consultation.

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12  
13 *Subtheme 1: Healthy lifestyles.* Participants alluded to primary care's role supporting people  
14 with learning disabilities in preventative approaches to healthcare, accessing public health  
15 promotion campaigns, and supporting healthy behaviours and choices (e.g. diet, exercise) (R2).

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17  
18 A GP said: '*To understand that making healthy choices around food is really important. People*  
19 *without learning disabilities struggle on that. People with learning disabilities end-up with*  
20 *diabetes and struggle to manage it'* (R8).  
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28 *Subtheme 2: Supporting secondary and tertiary care access (R9).* Participants described the  
29 importance of planning follow-up to primary healthcare: '*some people may need a named*  
30 *individual to support them booking appointments, or accessing test results and follow-up*  
31 *appointments'* (relative) and '*sometimes they rely on carers to remind them that they have*  
32 *follow-up. I don't necessarily think they would remember'* (SHM). This sometimes required  
33 referral into another service for support and care co-ordination: '*It's thinking about practical*  
34 *safety nets, that will allow them not to become lost to follow-up'* (GP) and sharing health action  
35 plans with relevant health professionals to facilitate follow-up support (R9).  
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47 Recommendations informed by the thematic analysis, research, primary care guidance and  
48 consultation with key stakeholders, were co-produced with an advisory group led by people  
49 learning disabilities (Table 1).  
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Table 1 Ten Recommendations: co-created suggestions for improving annual health checks for people with learning disabilities

R1	<i>Call them 'yearly' health checks</i>	The health check should take place every year, 'yearly'. People should know that this does not stop them from seeing a doctor at other times if they have a health problem
R2	<i>Create a supportive practice</i>	Creating a supportive practice involves making accommodations and prioritizing the needs of people with learning disabilities and may require adjusting practice. 'Personalisation' and making reasonable adjustments can make a big difference to helping the checks work well for people, and creating a supportive practice. Sharing examples of good practice can improve how support is given. Having a practice champion can help with this.
R3	<i>Use a screening tool</i>	Screening tools (learning disability inclusion tools) can be used to help understand what people's needs are and show if they might have a learning disability. Keeping registers up to date is important.
R4	<i>Be proactive!</i>	Contact people to attend, and follow-up if they do not attend. People need to know why they are being asked to get a health check and what will happen. Check people have information in a way they can understand.
R5	<i>Offer personalised appointments</i>	Ask if the check is a good time for them, and if it is somewhere they can go to. Offer longer appointments so checks are not done in a hurry. Find out what support people might need.
R6	<i>In the appointment speak to the person directly</i>	Speak to the person with a learning disability first, it's their health, even if they have someone supporting them. Let the person know what will happen and ask questions, even if it takes a bit longer.
R7	<i>Provide easy-read information or picture-questionnaires</i>	Make co-developed easy-read information the same for all practices. Give information about what will happen before the appointment. Use easy-read questionnaires to collect details or for health action planning. Give people information about their health to take away with them.
R8	<i>Make public health and health promotion information accessible</i>	Provide online easy-read public health and health promotion resources (e.g. on diet and exercise). These can be printed and handed to the person, posted, or emailed. It does not matter where you live, if the same easy-read information is being used across the country.
R9	<i>Support transfer and access to other health services where needed</i>	If people need to be seen by another health service after their check, they may need accessible information about this. They may need support to transfer to follow-up services successfully. A learning disability nurse could help with this.

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3 R10 *Have an accessibility* Have a named team member who keeps up to date with information about working with and caring for people  
4 *champion* with learning disabilities. They should link to a regional lead person who shares good practice and training  
5 opportunities.  
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## 2 Discussion

3 Five themes were identified and ten recommendations co-developed, describing approaches to  
4 improve primary care access for people with learning disabilities. Aligned with previous  
5 research, participants emphasized prioritizing people with learning disabilities, given their  
6 susceptibility to health inequalities, high mortality and comorbidity.<sup>1 5 17</sup> Previous research  
7 supports health checks for identification of treatable health conditions,<sup>11 12</sup> however in this  
8 study the quality of health checks varied. Primary care practices where development of services  
9 for people with learning disabilities is passively endorsed, may be less likely to proactively  
10 implement service improvements.<sup>21</sup> Aligned with this the current study found proactive  
11 prioritization of people with learning disabilities was facilitated by champions who supported  
12 initiatives including more thorough health checks and time for longer appointments.

13 In common with previous research, incorrect coding for learning disability was a challenge to  
14 prioritizing people with learning disabilities.<sup>14 15</sup> When participants were unaware someone  
15 had a learning disability, this was a barrier to prioritizing them, and offering appropriate  
16 healthcare and adjustments. Participants indicated a proactive approach to addressing this is  
17 required, including accurate, and reliable methods of identification as described in previous  
18 research.<sup>5 7 14</sup> Previous research describes barriers to people with learning disabilities accessing  
19 primary care including difficulty understanding and communicating symptoms, lack of an  
20 advocate, lack of assertiveness and living in unsupported settings.<sup>22 24 26</sup> In this study the  
21 importance of primary care proactively reaching-out to encourage attendance at health checks  
22 and facilitate follow-up healthcare was clear. People with learning disabilities were sometimes  
23 unaware they could have a health check, and aligned with previous research this highlights the  
24 role of direct support staff and importance of training on the health needs of people with  
25 learning disabilities.<sup>34</sup> Training and experiential learning have been found effective in reducing  
26 barriers to primary care for people with learning disabilities.<sup>33 36 32</sup> In accordance with this,

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3 27 training the broader primary care team including receptionists, sharing good practice via  
4  
5 28 demonstrating annual health checks and targeted support for practices, were found effective at  
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7 29 increasing health checks and service improvement in this study. UK national guidance <sup>10</sup>  
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9  
10 30 highlights the value of learning disability champions, and in this study practitioners with the  
11  
12 31 role were key to driving primary care improvement and innovation, through training, data  
13  
14 32 collection and support for practices less experienced in the care of people with learning  
15  
16 33 disabilities (R10). Important training topics identified in this study included learning  
17  
18 34 disabilities coding, reasonable adjustments, and national guidance initiatives.

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22 35 In accordance with research on improving comprehensibility of health questionnaires,  
23  
24 36 participants valued receiving accessible information before, and during primary healthcare  
25  
26 37 appointments, especially when they were afraid of attending. <sup>30 22</sup> However, previous research  
27  
28 38 highlighted accessible information is not always available and needs to be individualised; <sup>28 29</sup>  
29  
30 39 this was reflected in our fourth theme of personalisation. A bespoke, flexible and personalised  
31  
32 40 service (e.g. the receptionist knowing your name), went some way to addressing barriers faced  
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34 41 by people with learning disabilities in primary care. However, it was clear more innovation is  
35  
36 42 required with consideration of accessibility and service to service-user alignment in broader  
37  
38 43 contexts. These included automated telephone and check-in systems, embedding relevant easy-  
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40 44 read information into long-term condition management templates and health checks, and  
41  
42 45 facilitating staff awareness of reasonable adjustments (some participants reporting limited  
43  
44 46 understanding). Aligned with previous research promoting a more active role for people with  
45  
46 47 learning disabilities in healthcare interactions, <sup>27</sup> participants in this study valued  
47  
48 48 communication directed to the person with a learning disability when attending with a  
49  
50 49 supporter.

51  
52 50 Participants highlighted the importance of accessible health promotion, public health  
53  
54 51 information and resources, and primary care services who planned ahead, considering support

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3 52 for people with learning disabilities and families along pathways into secondary or tertiary  
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5 53 care. A care co-ordinator or learning disability nurse may be required, for example to support  
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7 54 hospital admission, so people with learning disabilities do not get lost to follow-up. In  
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10 55 accordance with previous research on preventative healthcare,<sup>23</sup> bridging agencies and  
11  
12 56 providers onwards from primary care requires a proactive organisational-level approach.

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15 57 A strength of the study is exploring the views of four stakeholder groups, and using the  
16  
17 58 information gathered to co-produce recommendations informed by stakeholder consultation. A  
18  
19 59 regional inner-city GP practice affirmed utility of the recommendations (saying all seemed  
20  
21 60 practical and could be implemented within practice); and indicated the key to change was a  
22  
23 61 named practice-lead, linked through regional primary care networks who could implement the  
24  
25 62 recommendations. The study has a number of limitations; online data collection may have  
26  
27 63 impeded establishing rapport, we collected limited demographic characteristics, and use of  
28  
29 64 convenience sampling in the North East UK may have limited representativeness. At the time  
30  
31 65 of the study primary care services were still being impacted by COVID-19, and under other  
32  
33 66 circumstances, perceptions regarding primary healthcare may have differed. Changes in  
34  
35 67 practice were described including more virtual consultations which in accordance with  
36  
37 68 previous research were found acceptable.<sup>39</sup>

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43 69 In conclusion all stakeholders highlighted misalignment in the primary care interface with the  
44  
45 70 needs of people with learning disabilities. Improvements in primary care services to best meet  
46  
47 71 the needs of people with learning disabilities continue to be required. The co-produced  
48  
49 72 recommendations can be used immediately, as a complement to existing guidance and as a  
50  
51 73 summary to guide training and service development. Future research should explore  
52  
53 74 standardised methods of identifying and coding reasonable adjustments, and innovation to  
54  
55 75 improve access to the primary care interface, including automated phone and check-in systems.  
56  
57 76 The study findings accord with the crucial role of learning disability leads, providing strategic  
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3 77 support to prioritize the healthcare needs of people with learning disabilities and drive service  
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5 78 improvements and innovation.  
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7

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9  
10 106 they contain information that could compromise the privacy of research participants. Some  
11  
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14 108 author (SH).  
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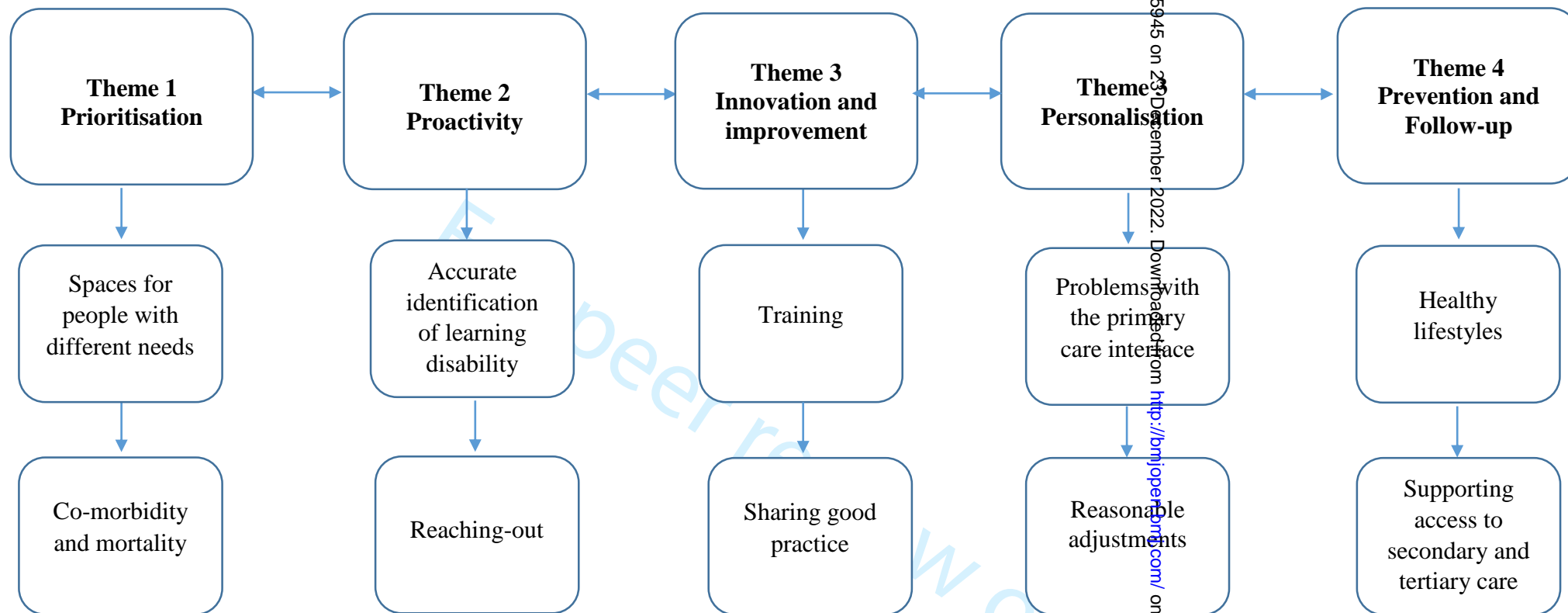


Figure 1 Structure of themes and subthemes



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3 *Online Supplementary Materials 1 (OS1).*  
4

5 **Focus group/interview and survey topic schedule for people with learning disabilities**  
6 **and relatives**  
7

8 At the focus groups, we will talk about health checks. By health checks, we mean going to  
9  
10 the doctors or GPs each year to talk about your health and to have some checks done. “It’s  
11  
12 like a full MOT for the body, to check if you are healthy.”  
13  
14

15  
16 We will ask the following questions in the focus group  
17

18 Thank you for agreeing to take part in our focus group

19 What things make it difficult for people with learning disabilities to go to the GP?

20 What things make it easier for people with learning disabilities to go to the GP?

21 What training should people working at the GPs have? (E.g. receptionists)

22 What do people think of health checks? Are they important?

23  
24 One thing that stops people getting the best health care is that others do not know they have a  
25 learning disability.  
26

27 What if someone had a learning disability but the GP didn’t know about it?

28 We are thinking a questionnaire might be good to help with this

29  
30 1. What do you think the good things would be about using a questionnaire to help the GP  
31 know if someone had a learning disability? (For example, finding out they had a learning  
32 disability, others understanding more about them)

33  
34 2. What do you think are the main bad things? (For example feeling embarrassed/shocked to  
35 find out)

36 Suggestions...

37 Complete the following sentence... Health checks are ...

- 38 • Important
- 39 • Necessary
- 40 • A waste of time
- 41 • Good thing if you’re offered them

42  
43 How have people found health checks/ what are people’s expectations and experiences of  
44 health checks?

45  
46 Is there anything that you would like to improve about having your/ your relative’s health  
47 check?

48  
49 Any other comments?  
50  
51  
52  
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3 How can access to the GPs for people with severe/profound learning disabilities, be  
4 improved? (*Relatives*)  
5

6 Can you think of any reasons why you/ your relative would not want a health check?  
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3 *Online Supplementary Materials 2 (OS2).*  
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5 **Interview Schedule for GPs, nurse practitioners and sheltered housing managers**  
6

7  
8 Part 1. Annual Health checks  
9

- 10
- 11 • In your view, how are annual health checks for people with learning disability working  
12 at the moment? Do the health checks take place on an annual basis?  
13
  - 14 • What systems do you have in place that alerts you to an annual health check being due  
15 to be carried out?  
16
  - 17 • When someone new joins the surgery does their record automatically flag if they have  
18 a learning disability and need an annual health check?  
19
  - 20 • Do some people decline a health check? If so, why?  
21
- 22

23  
24  
25  
26 Part 2. Learning disability inclusion tool – *reported elsewhere*  
27

28  
29 Part 3 A. Barriers to people with learning disability accessing primary care  
30

- 31
- 32 • In your view what are the main barriers to people with learning disability accessing  
33 primary care?  
34
  - 35 • What do you think are the main environmental barriers?  
36
  - 37 • What do you think are the main social barriers? (e.g. attitudinal issues, communication  
38 issues, phobias, prejudice)  
39
  - 40 • What things in your surgery or systems make it difficult for people with learning  
41 disability to get their annual health check?  
42
  - 43 • What improvements could be made within NHS systems to help people with learning  
44 disability have regular health checks?  
45
- 46

47  
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49  
50  
51  
52 2. What are the barriers to follow-up after primary care and implementation of a health plan?  
53

54  
55 Part 4. Reasonable adjustments  
56

- 57
- 58 • What things in your surgery or systems work well for people with learning disabilities  
59 getting their annual health check, and what could be improved?  
60

- 1  
2  
3 • What reasonable adjustments facilitate people with learning disability accessing  
4 primary care?  
5  
6

7  
8 Part 5. COVID-19  
9

- 10 • What mitigation is required to be in place in primary care settings for people with  
11 learning disability in the context of COVID-19?  
12  
13 • In respect of health checks for people with learning disabilities what have you learned  
14 from COVID-19?  
15  
16 • What changes would you incorporate going forwards?  
17  
18 • Is there someone within the surgery provision that could set up or audit people's  
19 capacities for phone and online appointments?  
20  
21 • How can people with learning disabilities be supported to accessing the GP more often  
22 during COVID-19?  
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## Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

### Title and abstract

<p><b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1/line 3
<p><b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 2/ line 34

### Introduction

<p><b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Line 77-123
<p><b>Purpose or research question</b> - Purpose of the study and specific objectives or questions</p>	Line 120-123

### Methods

<p><b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Line 125-127
<p><b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Line 167-169
<p><b>Context</b> - Setting/site and salient contextual factors; rationale**</p>	Line 130-141
<p><b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Line 130-141
<p><b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Line 127-128 and 132-138
<p><b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Line 125-126 Line 143-154

1 2 3 4 5	<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Line 142-156
6 7 8	<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Line 180-184
9 10 11 12	<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Line 168-172 Line 174-178
13 14 15 16	<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Line 168-172 Line 174-178
17 18 19 20	<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Line 174-178

## Results/findings

23 24 25 26	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Line 179-337 Figure 1 Table 1
27 28 29	<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Line 179-337

## Discussion

32 33 34 35 36 37	<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Line 340-416
38 39	<b>Limitations</b> - Trustworthiness and limitations of findings	Line 400-404

## Other

42 43 44	<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Line 435
45 46	<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Line 428-434

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: [10.1097/ACM.0000000000000388](https://doi.org/10.1097/ACM.0000000000000388)

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# BMJ Open

## Improving access to primary care and annual health checks for people who have a learning disability. A multi-stakeholder qualitative study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2022-065945.R2
Article Type:	Original research
Date Submitted by the Author:	29-Nov-2022
Complete List of Authors:	Wigham, Sarah; Newcastle University Faculty of Medical Sciences, Population Health Sciences Institute Bourne, Jane; Cumbria Northumberland Tyne and Wear NHS Foundation Trust McKenzie, K ; Northumbria University, Rowlands, Gill; Newcastle University, Population Health Sciences Institute Petersen, Katharine; Forum Family Practice Hackett, Simon; Newcastle University
<b>Primary Subject Heading</b>:	General practice / Family practice
Secondary Subject Heading:	Mental health
Keywords:	EDUCATION & TRAINING (see Medical Education & Training), Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, PRIMARY CARE

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32 **Corresponding Author:** Sarah Wigham

1  
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3 34 **Abstract**  
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5 35 Objectives: To investigate key stakeholders' views on how to improve access to primary care  
6  
7  
8 36 in general practice settings for people with learning disabilities (or intellectual disabilities).  
9  
10 37 Further to explore how inequalities and barriers in specific areas including annual health checks  
11  
12 38 might be addressed.

13  
14 39 *Design:* A qualitative study design was utilized with data collected during focus groups,  
15  
16  
17 40 interviews and open-response surveys; data analysis was thematic and informed by stakeholder  
18  
19 41 consultation. Processes to facilitate quality included triangulation of stakeholder perspectives,  
20  
21 42 triangulation of data collection methods, and checking interpretation of findings with  
22  
23 43 participants.

24  
25 44 *Setting:* UK regional services including learning disability organisations, primary care general  
26  
27 45 practitioner clinical practice networks and supported housing organisations.

28  
29 46 *Participants:* Sixteen people participated in the study: 4 people with learning disabilities  
30  
31 47 participated in a focus group; 4 relatives completed an interview or survey; 8 GPs, practice  
32  
33 48 nurses and supported housing managers participated in interviews.

34  
35 49 *Results:* Five overarching themes describing approaches to improve primary care access for  
36  
37 50 people with learning disabilities were identified including: prioritisation, proactivity,  
38  
39 51 innovation and improvement, personalisation and prevention and follow-up. Definitions of  
40  
41 52 themes were described and illustrated with quotes. Ten recommendations informed by the  
42  
43 53 thematic analysis, stakeholder consultation, research and primary care guidance were co-  
44  
45 54 developed with people with learning disabilities.

46  
47 55 *Conclusions:* All stakeholders identified problems, with primary care interfaces being  
48  
49 56 misaligned with the needs of people with learning disabilities. The recommendations informed  
50  
51 57 by all stakeholders can be used to guide development of service provision to better meet the  
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3 58 needs of people with learning disabilities in primary care. Future research should explore  
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6 59 professionals' understanding of reasonable adjustments.  
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3 **62 Article Summary: *Strengths and limitations of this study***  
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- 5  
6 **63**     • Qualitative data were collected from 16 key stakeholders (people with learning  
7  
8 **64**        disabilities, relatives, general practitioners, practice nurses and sheltered housing  
9  
10 **65**        managers) on ways to improve primary care access for people with learning disabilities.  
11  
12 **66**     • Stakeholder consultation informed study design and interpretation of research findings  
13  
14  
15 **67**        and recommendations were co-developed with people with learning disabilities.  
16  
17 **68**     • We used convenience sampling and the number of participants was small though this  
18  
19 **69**        is appropriate for qualitative designs.  
20  
21  
22 **70**     • Different methods of data collection were utilized, perspectives were triangulated  
23  
24 **71**        across key stakeholders and interpretation of the research findings was checked with  
25  
26 **72**        research participants.  
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31 **74** Keywords: primary care; learning disabilities, health checks, health inequalities  
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35 **76** **Word Count:** 4070  
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## 77 **Introduction**

78 People with learning disabilities experience higher burden of chronic disease and were at  
79 increased risk of hospitalization and mortality during the COVID-19 pandemic compared to  
80 the general population.<sup>1-3 4</sup> Given these health vulnerabilities, prioritizing the health needs of  
81 people with learning disabilities is crucial.<sup>5</sup> Guidance addressing this includes standards of  
82 care published in Canada;<sup>6 7</sup> and United Kingdom (UK) recommendations encompass annual  
83 health checks, learning disability registers, reasonable adjustments, and champions to share  
84 good practice.<sup>8-10</sup>

85 Annual health checks can uncover previously unknown conditions,<sup>11</sup> reduce preventable  
86 emergency hospitalizations,<sup>12</sup> allow monitoring treatments and foster continuity of care.<sup>7</sup>

87 Annual health checks are structured assessments conducted by General Practitioners (GPs) and  
88 practice nurses who facilitate access for people with learning disabilities into healthcare  
89 services.<sup>13</sup>

90 Learning disability registers, and diagnostic codes for clinical terms ('READ' or SNOMED  
91 [Systematized Nomenclature of Medicine] codes) used in the UK NHS facilitate identifying  
92 people attending primary care who may have a learning disability (NHS Digital). However,  
93 people may be un-coded or incorrectly coded; without correct coding for learning disability  
94 they cannot gain access to appropriate healthcare and adjustments. Methods of identifying  
95 people with learning disabilities in primary care are required.<sup>14 15</sup>

96 Despite initiatives and financial incentivisation for annual health checks,<sup>16</sup> barriers in primary  
97 healthcare persist for people with learning disabilities. Examples include low uptake of health  
98 checks,<sup>17</sup> and women with learning disabilities being less likely than those without to have  
99 cervical cancer screening or physiotherapy.<sup>18 19</sup> Further, while prevalence of long-term  
100 conditions in primary care (e.g. diabetes), is higher among people with learning disabilities,

1  
2  
3 101 best-practice condition-management indicators are lower relative to the general population.<sup>20</sup>

4  
5 102 In a study examining barriers to improving primary care for people with learning disabilities

6  
7 103 in Canada, services in which leadership only passively supported innovation were less likely

8  
9 104 to implement care improvements.<sup>21</sup>

10  
11  
12  
13 105 Other barriers in primary care for people with learning disabilities, include fear, carer

14  
15 106 unawareness of health problems,<sup>22</sup> and lack of evidence-based lifestyle interventions (e.g.

16  
17 107 obesity prevention).<sup>23</sup> People with learning disabilities may lack assertiveness, communication

18  
19 108 skills, and carers to support primary care attendance, and have difficulties self-managing health

20  
21 109 needs.<sup>24 22 25 17</sup> In the United States, adults with learning disabilities living unsupported had

22  
23 110 more emergency hospital visits compared with other residency types.<sup>26</sup> Reviews of service

24  
25 111 user and carer perspectives on barriers to accessing primary care, identified time, knowledge,

26  
27 112 awareness, training, communication, embarrassment and active involvement in healthcare

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29 113 decision-making as factors.<sup>24 27</sup>

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33 114 Access to primary care for people with learning disabilities can be facilitated by individualised

34  
35 115 easy-read information,<sup>28 29</sup> health questionnaires,<sup>30</sup> longer appointments,<sup>17</sup> assisting those

36  
37 116 living unsupported,<sup>26</sup> and having a proactive,<sup>7</sup> flexible approach to suit the person.<sup>31</sup>

38  
39 117 Practitioner and direct support staff training can also reduce barriers.<sup>32 33 34</sup> Practitioners may

40  
41 118 lack confidence working with people with learning disabilities,<sup>35</sup> and experiential learning was

42  
43 119 found beneficial for physicians in Canada.<sup>36</sup>

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47 120 While research into primary care for people with learning disabilities is growing, co-produced

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49 121 research across different stakeholders is sparse. This study aimed to elicit key stakeholder

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51 122 views on ways to improve GP primary care access for people with learning disabilities, and co-

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53 123 produce recommendations.

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57 124 **Methods**

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3 125 The study was qualitative. Data were collected during focus groups, interviews and surveys,  
4  
5 126 from June-December 2021 by the first and second authors. Analysis was thematic with an  
6  
7 127 inductive experiential framework informed by stakeholder consultation. Newcastle University  
8  
9 128 Research Ethics Committee provided ethical approval (Ref: 2102/10380/2020).

### 129 *Participants*

130 Recruitment was purposive to capture a range of stakeholder perspectives. Inclusion criteria  
131 were adults (>18 years of age) with mild to moderate learning disabilities, defined as having  
132 capacity to consent to participate in the research. People with learning disabilities were  
133 recruited via a UK regional charity who distributed accessible study information to people with  
134 learning disabilities and informed the research team of those meeting inclusion criteria and  
135 interested in participating. Prior to meeting the researcher accessible study information was  
136 read with people with learning disabilities by an advocate. Following this the information was  
137 read with people with learning disabilities by the first author who also asked questions about  
138 the information to assess understanding and capacity to informed consent. Relatives of adults  
139 with learning disabilities were recruited via a regional charity and contacts network who  
140 distributed study information and researcher details.

141 GPs, practice nurses and sheltered housing managers were recruited through regional clinical  
142 and practitioner networks.

### 143 *Data collection*

144 Online data were collected using Microsoft Teams after completion of informed consent. An  
145 online focus group was conducted with people with learning disabilities and supported by an  
146 advocate who facilitated online access. Data collection from relatives was by online interview  
147 or survey depending on their preference. The survey comprised the same open-response  
148 questions as the interview schedule. During focus groups and interviews, prompts were used  
149 to elicit detail, for example: can you tell me more about that? Key points from the focus group



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2  
3 150 with people with learning disabilities were summarized by the researcher and read back to the  
4  
5 151 group to check accuracy. Interviews with relatives were audio-recorded and transcribed. The  
6  
7 152 focus groups, interview and survey topic schedules are shown in the Online Supplementary  
8  
9 153 materials (OS1).

10  
11  
12  
13 154 Online semi-structured interviews conducted with GPs, nurse practitioners and sheltered  
14  
15 155 housing managers were audio-recorded and transcribed. The interview schedule (OS2)  
16  
17 156 comprised five sections: annual health checks, learning disability inclusion tools, barriers  
18  
19 157 accessing primary care, reasonable adjustments and COVID-19. Data on inclusion tools is  
20  
21 158 reported elsewhere.<sup>37</sup> All participants were sent a debrief email.

### 22 23 24 25 26 159 *Patient and Public Involvement*

27  
28 160 Study documents (consent, information sheets, focus group topic guides) were developed in  
29  
30 161 consultation with a research advisory group led by people with learning disabilities. Feedback  
31  
32 162 included to add content, edit wording, and create a debrief document. GPs were consulted  
33  
34 163 regarding the interview topic schedule, and advised on wording and content. Initial review of  
35  
36 164 data indicated living arrangements impact primary care access; this was discussed with a GP  
37  
38 165 and informed our decision to recruit sheltered housing managers. An online presentation of  
39  
40 166 preliminary findings was made to a research advisory group led by people with learning  
41  
42 167 disabilities. Study findings were presented to a GP practice meeting.

### 43 44 45 46 47 168 *Analysis*

48  
49  
50 169 Thematic analysis was conducted manually by the first and last authors (an experienced  
51  
52 170 clinician and researcher in the field of learning disabilities) in iterative phases following  
53  
54 171 anonymization: (1) data familiarisation (2) coding (3) developing a coding framework (4)  
55  
56 172 identifying themes (5) reviewing, revising and confirming themes and definitions (6) and  
57  
58 173 identifying illustrative quotes.<sup>38 39</sup> Informed by thematic analysis findings, research, primary

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2  
3 174 care guidance and consultation with key stakeholders, recommendations were co-produced  
4  
5 175 with people with learning disabilities (Table 1). In accordance with qualitative analysis best-  
6  
7  
8 176 practice, trustworthiness was ensured by: checking interpretation of findings with participants,  
9  
10 177 triangulating perspectives and important aspects of the topic by collecting data from different  
11  
12 178 stakeholders using different methods, and by inviting participants to comment on a summary  
13  
14  
15 179 of findings.<sup>38 39</sup>

## 17 180 **Results**

18 181 Sixteen people participated comprising 4 people with learning disabilities (1 male; 3 female);  
19  
20 182 four relatives (all female); and eight GPs, practice nurses and supported housing managers (7  
21  
22 183 female; 1 male). GPs, practice nurses, supported housing managers and one relative completed  
23  
24 184 interviews, four people with learning disabilities took part in a focus group, and three relatives  
25  
26 185 completed surveys. Five themes with subthemes were identified from the focus group,  
27  
28 186 interviews and survey data: prioritisation, proactivity, innovation and improvement,  
29  
30 187 personalisation, prevention and follow-up (Figure 1).

31 188 At the time of the study primary care services were still under considerable pressure from the  
32  
33 189 impact of COVID-19, and participants described changes to healthcare delivery including use  
34  
35 190 of virtual technology: *'there was lots of Facetime consultation'* (sheltered housing manager:  
36  
37 191 SHM) and *'we had to put them (health checks) all on hold'* (GP). Some changes worked well  
38  
39 192 and were adopted longer-term: *'Now we've got the technology in place, it allows patient*  
40  
41 193 *choice if somebody finds it more comfortable with consultation by video or phone'*. However,  
42  
43 194 this wasn't always suitable: *'There are bits of health checks that need to be done face-to-face;*  
44  
45 195 *you can't do a breast or testicle check over the phone or video'*.

46  
47  
48 196 *(Figure 1 here)*

49  
50  
51 197 *Theme 1: Prioritisation*

1  
2  
3 198 This theme described the rationale for prioritizing people with learning disabilities in primary  
4  
5 199 care, and how to support this (Recommendation: R2), and comprised two subthemes: spaces  
6  
7  
8 200 for people with different needs, and co-morbidity and mortality.  
9

10  
11 201 *Subtheme 1: Spaces for people with different needs*

12  
13 202 Participants indicated that waiting rooms may put people off attending and suggested the  
14  
15 203 benefits of spaces for people with learning disabilities: *'He doesn't like to go because of how*  
16  
17 204 *busy it can get...loads of noises... distractions...he has anxiety...if he's making noises and he's*  
18  
19  
20 205 *aware of people looking at him' (SHM)*. Participants also valued being seen promptly  
21  
22 206 *'sometimes the GP will see my daughter on time, this has happened more recently as I've*  
23  
24 207 *explained my daughter's inability to wait and her anxiety' (relative)*. A participant with a  
25  
26 208 learning disability said *'you don't know how long they (the GP) are going to be, it's not always*  
27  
28 209 *5-minutes, then you get flustered because the doctor wasn't on time'.*

30  
31  
32 210 *Subtheme 2. Co-morbidity and mortality*

33  
34 211 Given prevalence of multiple health conditions and high mortality among people with learning  
35  
36 212 disabilities relative to the general population, participants said unless they are prioritised health  
37  
38 213 conditions may be missed: *'If any of the people on this [learning disability] list, ring*  
39  
40 214 *for help, they go to the top of the queue. So that's the culture we're trying to develop in our*  
41  
42 215 *practice, to minimize the risk of stuff being missed' (GP)*.

43  
44  
45  
46 216 Primary care checks were viewed key to identifying preventable health conditions, and  
47  
48 217 important as people with learning disabilities may find it difficult to manage multiple-health  
49  
50 218 conditions: *'We have patients at high risk of avoidable illness and preventable mortality, have*  
51  
52 219 *another long-term condition to manage, which is really difficult and puts them at higher risk*  
53  
54 220 *of death' (GP)*.

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3 221 Prioritization required allocating resources; participants described offering longer  
4  
5 222 appointments and allowing enough time for thorough health checks for patients with learning  
6  
7 223 disabilities (R5): *'People who are enthusiastic [about annual health checks] and see their value,*  
8  
9 224 *do them more thoroughly. Some people will just put a few biometric results into a template...a*  
10  
11 225 *health check needs to be a multi-system review, taking into context biological, psychological,*  
12  
13 226 *sociological circumstances and needs to act on what it finds' (GP).*

17  
18 227 *Theme 2: Proactivity (R4)*

19  
20 228 A recurring theme described by participants was the importance of proactively encouraging  
21  
22 229 people with learning disabilities to attend primary care. The theme comprised two subthemes:  
23  
24 230 accurate identification and reaching-out.

25  
26  
27  
28 231 *Subtheme 1. Accurate identification (R3)*

29  
30 232 In order to prioritise people, practices need to know which patients have a learning disability:  
31  
32 233 *'we know people with learning disabilities have premature avoidable mortality. The only way*  
33  
34 234 *we can do something about that is to proactively identify them and bring them in' (GP).*  
35  
36 235 Identification of patients with learning disabilities required the correct diagnostic codes, use of  
37  
38 236 registers, screening, and multi-agency working: *'We need to work together, general practice,*  
39  
40 237 *paediatrics and hostels' because 'if you don't have the right code, you don't get the*  
41  
42 238 *[appropriate] health-care' (GP).*

43  
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47 239 *Subtheme 2: Reaching-out:* Participants explained that it was important to reach-out to people  
48  
49 240 with learning disabilities who may be unaware of health service entitlements. While  
50  
51 241 participants with learning disabilities could see the value of health checks: *'they are important,*  
52  
53 242 *and can tell you if things are getting worse' and 'there's no reason I wouldn't want one', one*  
54  
55 243 person with a learning disability said there was *'no sign saying you're allowed a health check,*  
56  
57 244 *I didn't know I could get one'. A relative described inconsistent service provision: 'health*  
58  
59  
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3 245 *checks have been hit-and-miss*', while a sheltered housing manager said *'sometimes the people*  
4  
5 246 *we support don't know what an annual health check is*'.

6  
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8  
9 247 Participants said that *'people decline them [health checks], and we have to chase around for*  
10  
11 248 *them*' (GP). Reasons included *'fear of health professionals and settings from past experiences*  
12  
13 249 (relative), or feeling they don't need a health assessment and have no-one to advocate for them:  
14  
15 250 *'If a person is living independently, they may feel they don't want to bother the GP... a lot of*  
16  
17 251 *people with mild learning disabilities tend not to go to the GP so things can be missed*' (SHM).  
18  
19 252 Participants described the importance of reaching-out to people without an advocate: *'If people*  
20  
21 253 *don't have wrap-around support, they probably fall through the cracks*' (SHM).  
22  
23  
24

25  
26 254 Participants highlighted that people with learning disabilities may have atypical symptoms, and  
27  
28 255 they and carers may not understand symptom significance: *'It's hard to know if there's health*  
29  
30 256 *issues, when my son is non-speaking and unable to communicate pain or feelings*' (relative). A  
31  
32 257 GP said *'unless we provide proactive healthcare to people that might not present typically, we*  
33  
34 258 *risk their health*'. Methods of reaching-out included extra phone-calls, texts, offering  
35  
36 259 flexibility, follow-up of non-attenders and those unsupported, and supporting follow-up  
37  
38 260 healthcare arising from primary care visits (R4 & R9).  
39  
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41

### 42 261 *Theme 3: Innovation and improvement*

43  
44  
45 262 Theme 3 focussed on service development and comprised two subthemes: training and sharing  
46  
47 263 good practice.

48  
49 264 *Subtheme 1: Training*. Participants described how training improves primary care staff skills  
50  
51 265 and awareness; a GP commented: *'education of staff is really important, so they're aware these*  
52  
53 266 *patients might be phoning up*'. This was emphasized by a participant with a learning disability:  
54  
55 267 *'people on reception don't give you enough time, they rush you and you can make mistakes...if*  
56  
57 268 *they know you've a learning disability, they can talk to you in a different way*'. A relative  
58  
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3 269 suggested training on behaviours viewed as challenging would be helpful: *'receptionists should*  
4  
5 270 *have training to understand'*.

6  
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8  
9 271 *Subtheme 2: Sharing good practice.* Participants described how sharing good practice can  
10  
11 272 improve quality: *'there are various suboptimal [annual health check] templates being used.*  
12  
13 273 *Our CCG [clinical commissioning group] has been ensuring everybody uses the national*  
14  
15 274 *template. We demonstrated how to do annual health checks using the template'* (GP). Sharing  
16  
17  
18 275 good practice also included supporting less experienced practices: *'there was a strategic*  
19  
20 276 *approach from our CCG to share data monthly, about how each practice network was doing*  
21  
22 277 *with annual health checks, whether they were on target or not. There was help to practices*  
23  
24 278 *with poorer uptake'*. (GP)

25  
26  
27  
28 279 Participants described the importance of a named person supporting development and good  
29  
30 280 practice: *'I'm the learning disability lead...so it's my responsibility to make sure they're all*  
31  
32 281 *done [health checks]'* (R10) and *'the practice could have a designated lead, that everybody*  
33  
34 282 *recognises as the learning disability doctor or nurse'* (practice nurse) (R10).

35  
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38 283 *Theme 4. Personalisation (R2, R5)*

39  
40 284 A personalised service was valued, including for continuity of care, participants with learning  
41  
42 285 disabilities said: *'I know the nurses quite well, that's helpful'* and *'seeing the same GP, so they*  
43  
44 286 *get to know you a bit'*. Sub-themes included primary care interface problems and reasonable  
45  
46 287 adjustments.

47  
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49  
50 288 *Sub-theme 1. Primary care interface problems:* It was evident across all stakeholders that the  
51  
52 289 primary care interface was challenging to people with learning disabilities, including  
53  
54 290 automated telephone response options when phoning the surgery: *'A patient ringing-up with a*  
55  
56 291 *mild learning disability, might not be able to wait in a phone queue, and struggle with phone*  
57  
58 292 *numbers...if it says press '1'. Those things haven't been thought about for people with learning*

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3 293 *disabilities' (GP). A participant with a learning disability said they: 'might not be able to use*  
4  
5 294 *the check-in machine and put in a date of birth'. A GP described how: 'We only book four*  
6  
7  
8 295 *weeks ahead. If I say I need to see you in six-weeks, they can't book that appointment and need*  
9  
10 296 *to ring closer to the time. Someone who hasn't got a carer, will probably not remember'.*

11  
12  
13 297 *Sub-theme 2. Reasonable adjustments: A GP described how offering flexibility around health*  
14  
15 298 *checks improved uptake: 'We went from 49% uptake of annual health checks to 98%'. A*  
16  
17 299 *relative suggested 'ask if patients need any reasonable adjustments, and what would make the*  
18  
19 300 *visit easier' (R2 and R5), for example booking appointments at times to suit the person with a*  
20  
21 301 *learning disability and carer who could attend with them. A participant with a learning*  
22  
23 302 *disability said: 'they could talk for me if I didn't know the answer'. However, direct*  
24  
25 303 *communication from GPs or nurses was key, one participant with a learning disability saying:*  
26  
27 304 *'It's important to speak to the person; it's not nice to be talked over the top of' (R6).*

28  
29  
30  
31 305 *Other examples were provision of accessible information and avoiding jargon (R7 and R8); a*  
32  
33 306 *participant with a learning disability said: 'They should be called yearly health checks...yearly*  
34  
35 307 *is clearer than annual' (R1). Clear information before and during appointments was found*  
36  
37 308 *helpful by people with learning disabilities: 'Some people might be frightened' so 'letting*  
38  
39 309 *people know what to expect at their appointment makes it less scary' and 'I liked that I could*  
40  
41 310 *watch on You-tube what a health check is' (R7). A participant with a learning disability*  
42  
43 311 *described receiving a postal picture-questionnaire and said: 'you can fill in a form, if you're*  
44  
45 312 *afraid of needles' and 'I filled it in with help from my support worker'.*

46  
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49  
50 313 *Participants described gaps in awareness of accessible resources: 'It would be really helpful to*  
51  
52 314 *have a website that has all the common health conditions. If you've got asthma I can print*  
53  
54 315 *something off. There's a lot of medical terminology in leaflets we give people' (GP) (R7).*  
55  
56 316 *Limitations in reasonable adjustments provision was evident, a GP said: 'I'm rolling out the*  
57  
58 317 *idea of coding that patients need a reasonable adjustment. When I talk to practices they're not*

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3 318 *really doing it; it's in their heads but they're not making it visible*. A GP explained staff may  
4  
5 319 lack awareness: *'I think we need to talk about reasonable adjustments in a more accessible*  
6  
7 320 *way, even for professionals. They've got reasonable adjustments written on their notes; that*  
8  
9 321 *assumes our staff know what reasonable adjustments are*'.

## 322 **Theme 5: Prevention and Follow-up healthcare**

323 This theme focussed on supporting any follow-up resulting from primary care consultation and  
324 comprised two subthemes including healthy lifestyles and supporting secondary and tertiary  
325 care access.

326 *Subtheme 1: Healthy lifestyles.* Participants alluded to primary care's role supporting people  
327 with learning disabilities in preventative approaches to healthcare, accessing public health  
328 promotion campaigns, and supporting healthy behaviours and choices (e.g. diet, exercise) (R2).  
329 A GP said: *'To understand that making healthy choices around food is really important. People*  
330 *without learning disabilities struggle on that. People with learning disabilities end-up with*  
331 *diabetes and struggle to manage it*' (R8).

332 *Subtheme 2: Supporting secondary and tertiary care access (R9).* Participants described the  
333 importance of planning follow-up to primary healthcare: *'some people may need a named*  
334 *individual to support them booking appointments, or accessing test results and follow-up*  
335 *appointments*' (relative) and *'sometimes they rely on carers to remind them that they have*  
336 *follow-up. I don't necessarily think they would remember*' (SHM). This sometimes required  
337 referral into another service for support and care co-ordination: *'It's thinking about practical*  
338 *safety nets, that will allow them not to become lost to follow-up*' (GP) and sharing health action  
339 plans with relevant health professionals to facilitate follow-up support (R9).



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340 Recommendations informed by the thematic analysis, research, primary care guidance and  
341 consultation with key stakeholders, were co-produced with an advisory group led by people  
342 learning disabilities (Table 1).  
343

For peer review only

Table 1 Ten Recommendations: co-created suggestions for improving annual health checks for people with learning disabilities

R1	<i>Call them 'yearly' health checks</i>	The health check should take place every year, 'yearly'. People should know that this does not stop them from seeing a doctor at other times if they have a health problem
R2	<i>Create a supportive practice</i>	Creating a supportive practice involves making accommodations and prioritizing the needs of people with learning disabilities and may require adjusting practice. 'Personalisation' and making reasonable adjustments can make a big difference to helping the checks work well for people, and creating a supportive practice. Sharing examples of good practice can improve how support is given. Having a practice champion can help with this.
R3	<i>Use a screening tool</i>	Screening tools (learning disability inclusion tools) can be used to help understand what people's needs are and show if they might have a learning disability. Keeping registers up to date is important.
R4	<i>Be proactive!</i>	Contact people to attend, and follow-up if they do not attend. People need to know why they are being asked to get a health check and what will happen. Check people have information in a way they can understand.
R5	<i>Offer personalised appointments</i>	Ask if the check is a good time for them, and if it is somewhere they can go to. Offer longer appointments so checks are not done in a hurry. Find out what support people might need.
R6	<i>In the appointment speak to the person directly</i>	Speak to the person with a learning disability first, it's their health, even if they have someone supporting them. Let the person know what will happen and ask questions, even if it takes a bit longer.
R7	<i>Provide easy-read information or picture-questionnaires</i>	Make co-developed easy-read information the same for all practices. Give information about what will happen before the appointment. Use easy-read questionnaires to collect details or for health action planning. Give people information about their health to take away with them.
R8	<i>Make public health and health promotion information accessible</i>	Provide online easy-read public health and health promotion resources (e.g. on diet and exercise). These can be printed and handed to the person, posted, or emailed. It does not matter where you live, if the same easy-read information is being used across the country.
R9	<i>Support transfer and access to other health services where needed</i>	If people need to be seen by another health service after their check, they may need accessible information about this. They may need support to transfer to follow-up services successfully. A learning disability nurse could help with this.

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R10 *Have an accessibility champion* Have a named team member who keeps up to date with information about working with and caring for people with learning disabilities. They should link to a regional lead person who shares good practice and training opportunities.

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For peer review only

## 345 **Discussion**

346 Five themes were identified and ten recommendations co-developed, describing approaches to  
347 improve primary care access for people with learning disabilities. Aligned with previous  
348 research, participants emphasized prioritizing people with learning disabilities, given their  
349 susceptibility to health inequalities, high mortality and comorbidity.<sup>1 5 17</sup> Previous research  
350 supports health checks for identification of treatable health conditions,<sup>11 12</sup> however in this  
351 study the quality of health checks varied. Primary care practices where development of services  
352 for people with learning disabilities is passively endorsed, may be less likely to proactively  
353 implement service improvements.<sup>21</sup> Aligned with this the current study found proactive  
354 prioritization of people with learning disabilities was facilitated by champions who supported  
355 initiatives including more thorough health checks and time for longer appointments.

356 In common with previous research, incorrect coding for learning disability was a challenge to  
357 prioritizing people with learning disabilities.<sup>14 15</sup> When participants were unaware someone  
358 had a learning disability, this was a barrier to prioritizing them, and offering appropriate  
359 healthcare and adjustments. Participants indicated a proactive approach to addressing this is  
360 required, including accurate, and reliable methods of identification as described in previous  
361 research.<sup>5 7 14</sup> Previous research describes barriers to people with learning disabilities accessing  
362 primary care including difficulty understanding and communicating symptoms, lack of an  
363 advocate, lack of assertiveness and living in unsupported settings.<sup>22 24 26</sup> In this study the  
364 importance of primary care proactively reaching-out to encourage attendance at health checks  
365 and facilitate follow-up healthcare was clear. People with learning disabilities were sometimes  
366 unaware they could have a health check, and aligned with previous research this highlights the  
367 role of direct support staff and importance of training on the health needs of people with  
368 learning disabilities.<sup>34</sup> Training and experiential learning have been found effective in reducing  
369 barriers to primary care for people with learning disabilities.<sup>33 36 32</sup> In accordance with this,

1  
2  
3 370 training the broader primary care team including receptionists, sharing good practice via  
4  
5 371 demonstrating annual health checks and targeted support for practices, were found to contribute  
6  
7 372 to increasing health checks and service improvement in this study. UK national guidance <sup>10</sup>  
8  
9 373 highlights the value of learning disability champions, and in this study practitioners with the  
10  
11 374 role were key to driving primary care improvement and innovation, through training, data  
12  
13 375 collection and support for practices less experienced in the care of people with learning  
14  
15 376 disabilities (R10). Important training topics identified in this study included learning  
16  
17 377 disabilities coding, reasonable adjustments, and national guidance initiatives.

18  
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21  
22 378 In accordance with research on improving comprehensibility of health questionnaires,  
23  
24 379 participants valued receiving accessible information before, and during primary healthcare  
25  
26 380 appointments, especially when they were afraid of attending. <sup>30 22</sup> However, previous research  
27  
28 381 highlighted accessible information is not always available and needs to be individualised; <sup>28 29</sup>  
29  
30 382 this was reflected in our fourth theme of personalisation. A bespoke, flexible and personalised  
31  
32 383 service (e.g. the receptionist knowing your name), went some way to addressing barriers faced  
33  
34 384 by people with learning disabilities in primary care. However, it was clear more innovation is  
35  
36 385 required with consideration of accessibility and service to service-user alignment in broader  
37  
38 386 contexts. These included automated telephone and check-in systems, embedding relevant easy-  
39  
40 387 read information into long-term condition management templates and health checks, and  
41  
42 388 facilitating staff awareness of reasonable adjustments (some participants reporting limited  
43  
44 389 understanding). Aligned with previous research promoting a more active role for people with  
45  
46 390 learning disabilities in healthcare interactions, <sup>27</sup> participants in this study valued  
47  
48 391 communication directed to the person with a learning disability when attending with a  
49  
50 392 supporter.

51  
52 393 Participants highlighted the importance of accessible health promotion, public health  
53  
54 394 information and resources, and primary care services who planned ahead, considering support

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3 395 for people with learning disabilities and families along pathways into secondary or tertiary  
4  
5 396 care. A care co-ordinator or learning disability nurse may be required, for example to support  
6  
7 397 hospital admission, so people with learning disabilities do not get lost to follow-up. In  
8  
9  
10 398 accordance with previous research on preventative healthcare, <sup>23</sup> bridging agencies and  
11  
12 399 providers onwards from primary care requires a proactive organisational-level approach.

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14  
15 400 A strength of the study is exploring the views of four stakeholder groups, and using the  
16  
17 401 information gathered to co-produce recommendations informed by stakeholder consultation. A  
18  
19 402 regional inner-city GP practice affirmed utility of the recommendations (saying all seemed  
20  
21 403 practical and could be implemented within practice); and indicated the key to change was a  
22  
23 404 named practice-lead, linked through regional primary care networks who could implement the  
24  
25 405 recommendations. The study has a number of limitations; online data collection may have  
26  
27 406 impeded establishing rapport, we collected limited demographic characteristics, and use of  
28  
29 407 convenience sampling in the North East UK may have limited representativeness. At the time  
30  
31 408 of the study primary care services were still being impacted by COVID-19, and under other  
32  
33 409 circumstances, perceptions regarding primary healthcare may have differed. Changes in  
34  
35 410 practice were described including more virtual consultations; in accordance with previous  
36  
37 411 research this format for consultation was found acceptable. <sup>40</sup>

38  
39 412 In conclusion all stakeholders highlighted misalignment in the primary care interface with the  
40  
41 413 needs of people with learning disabilities. Improvements in primary care services to best meet  
42  
43 414 the needs of people with learning disabilities continue to be required. The co-produced  
44  
45 415 recommendations can be used immediately, as a complement to existing guidance and as a  
46  
47 416 summary to guide training and service development. Future research should explore  
48  
49 417 standardised methods of identifying and coding reasonable adjustments, and innovation to  
50  
51 418 improve access to the primary care interface, including automated phone and check-in systems.  
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53 419 The study findings accord with the crucial role of learning disability leads, providing strategic  
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420 support to prioritize the healthcare needs of people with learning disabilities and drive service  
421 improvements and innovation.

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39 439 Social Care.  
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44 440 **Declaration of conflicting interests:** None to declare  
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46  
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48  
49 442 Investigator. SH, SW, JB, KM, KP & GR contributed to conceptualisation and development of  
50  
51 443 data collection materials. SW & JB collected data. SW and SH wrote the first draft of the  
52  
53 444 manuscript. SH, SW, JB, KM, KP & GR contributed during the editing and reviewing process.  
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56 445 All authors approved the final manuscript.  
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3 446 **Ethics:** Newcastle University Research Ethics Committee gave the study a favourable  
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5 447 opinion (Ref: 2102/10380/2020).  
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8 448 **Data sharing:** Data are available on reasonable request. The data are not publicly available as  
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10 449 they contain information that could compromise the privacy of research participants. Some  
11  
12 450 data that support the findings of this study are available on reasonable request from the last  
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14 451 author (SH).  
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576 Figure 1. Structure of themes and subthemes

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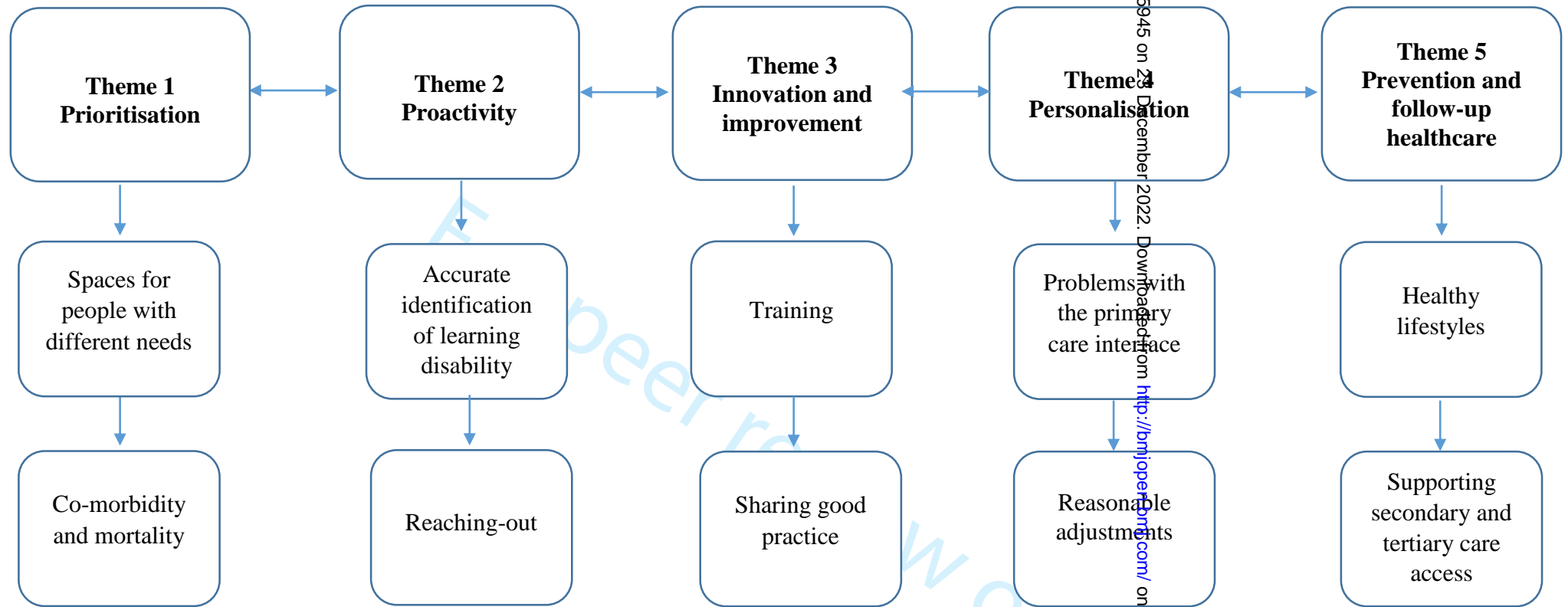


Figure 1 Structure of themes and subthemes

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3 *Online Supplementary Materials 1 (OS1).*  
4

5 **Focus group/interview and survey topic schedule for people with learning disabilities**  
6 **and relatives**  
7

8 At the focus groups, we will talk about health checks. By health checks, we mean going to  
9 the doctors or GPs each year to talk about your health and to have some checks done. “It’s  
10 like a full MOT for the body, to check if you are healthy.”  
11  
12

13 We will ask the following questions in the focus group  
14

15 Thank you for agreeing to take part in our focus group  
16

17 What things make it difficult for people with learning disabilities to go to the GP?  
18

19 What things make it easier for people with learning disabilities to go to the GP?  
20

21 What training should people working at the GPs have? (E.g. receptionists)  
22

23 What do people think of health checks? Are they important?  
24

25 One thing that stops people getting the best health care is that others do not know they have a  
26 learning disability.  
27

28 What if someone had a learning disability but the GP didn’t know about it?  
29

30 We are thinking a questionnaire might be good to help with this  
31

32 1. What do you think the good things would be about using a questionnaire to help the GP  
33 know if someone had a learning disability? (For example, finding out they had a learning  
34 disability, others understanding more about them)  
35

36 2. What do you think are the main bad things? (For example feeling embarrassed/shocked to  
37 find out)  
38

39 Suggestions...

40 Complete the following sentence... Health checks are ...  
41

- 42 • Important
- 43 • Necessary
- 44 • A waste of time
- 45 • Good thing if you’re offered them

46 How have people found health checks/ what are people’s expectations and experiences of  
47 health checks?  
48

49 Is there anything that you would like to improve about having your/ your relative’s health  
50 check?  
51

52 Any other comments?  
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2  
3 How can access to the GPs for people with severe/profound learning disabilities, be  
4 improved? (*Relatives*)  
5

6 Can you think of any reasons why you/ your relative would not want a health check?  
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3 *Online Supplementary Materials 2 (OS2).*  
4

5 **Interview Schedule for GPs, nurse practitioners and sheltered housing managers**  
6

7  
8 Part 1. Annual Health checks  
9

- 10
- 11 • In your view, how are annual health checks for people with learning disability working  
12 at the moment? Do the health checks take place on an annual basis?  
13
  - 14 • What systems do you have in place that alerts you to an annual health check being due  
15 to be carried out?  
16
  - 17 • When someone new joins the surgery does their record automatically flag if they have  
18 a learning disability and need an annual health check?  
19
  - 20 • Do some people decline a health check? If so, why?  
21
- 22

23  
24  
25  
26 Part 2. Learning disability inclusion tool – *reported elsewhere*  
27

28  
29 Part 3 A. Barriers to people with learning disability accessing primary care  
30

- 31
- 32 • In your view what are the main barriers to people with learning disability accessing  
33 primary care?  
34
  - 35 • What do you think are the main environmental barriers?  
36
  - 37 • What do you think are the main social barriers? (e.g. attitudinal issues, communication  
38 issues, phobias, prejudice)  
39
  - 40 • What things in your surgery or systems make it difficult for people with learning  
41 disability to get their annual health check?  
42
  - 43 • What improvements could be made within NHS systems to help people with learning  
44 disability have regular health checks?  
45
- 46

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51  
52 2. What are the barriers to follow-up after primary care and implementation of a health plan?  
53

54  
55 Part 4. Reasonable adjustments  
56

- 57
- 58 • What things in your surgery or systems work well for people with learning disabilities  
59 getting their annual health check, and what could be improved?  
60

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2  
3 • What reasonable adjustments facilitate people with learning disability accessing  
4 primary care?  
5  
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7  
8 Part 5. COVID-19  
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- 10 • What mitigation is required to be in place in primary care settings for people with  
11 learning disability in the context of COVID-19?  
12  
13 • In respect of health checks for people with learning disabilities what have you learned  
14 from COVID-19?  
15  
16 • What changes would you incorporate going forwards?  
17  
18 • Is there someone within the surgery provision that could set up or audit people's  
19 capacities for phone and online appointments?  
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21 • How can people with learning disabilities be supported to accessing the GP more often  
22 during COVID-19?  
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## Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

### Title and abstract

<p><b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1/line 3
<p><b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 2/ line 34

### Introduction

<p><b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Line 77-123
<p><b>Purpose or research question</b> - Purpose of the study and specific objectives or questions</p>	Line 120-123

### Methods

<p><b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	Line 125-127
<p><b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Line 167-169
<p><b>Context</b> - Setting/site and salient contextual factors; rationale**</p>	Line 130-141
<p><b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	Line 130-141
<p><b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	Line 127-128 and 132-138
<p><b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	Line 125-126 Line 143-154

1 2 3 4 5	<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Line 142-156
6 7 8	<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Line 180-184
9 10 11 12	<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Line 168-172 Line 174-178
13 14 15 16	<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Line 168-172 Line 174-178
17 18 19 20	<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Line 174-178

## Results/findings

23 24 25 26	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Line 179-337 Figure 1 Table 1
27 28 29	<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Line 179-337

## Discussion

32 33 34 35 36 37	<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Line 340-416
38 39	<b>Limitations</b> - Trustworthiness and limitations of findings	Line 400-404

## Other

42 43 44	<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Line 435
45 46	<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Line 428-434

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

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