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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 the views of key stakeholders on how access to primary care in general practice settings might be improved for people with learning disabilities. Further to explore how inequalities/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 surveys; data analysis was thematic and informed by stakeholder consultation. Processes to facilitate quality included triangulation of stakeholder perspectives/data collection methods, and checking interpretation of findings with participants.

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

Participants: Sixteen people participated in the study: 6 people with learning disabilities participated in two focus groups; 4 relatives completed interviews/surveys; 8 GPs, practice nurses and supported housing managers participated in interviews.

Results: Four overarching themes describing approaches to improve primary care access for people with learning disabilities were identified including: prioritisation, proactivity, personalisation and prevention. Definitions of themes were described and illustrated with quotes; a model was developed showing interconnection between themes, subthemes and service characteristics. Ten recommendations were developed informed by the thematic analysis, stakeholder consultation including people who have a learning disability, and research/primary care guidance.

Conclusions: All stakeholders identified problems regarding the ways in which primary care interfaces are misaligned with the needs of people with learning disabilities. The recommendations informed by all stakeholders can be used to guide service development for better service user/service provision fit to improve access to primary care for people with

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learning disabilities. Future research should explore professionals’ understanding of reasonable adjustments.

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Article Summary: *Strengths and limitations of this study*

- Qualitative data were collected from 16 key stakeholders (people with a learning disability, relatives, general practitioners, practice nurses and sheltered housing managers) on ways to improve primary care access for people with learning disabilities
- Stakeholder consultation informed study design and interpretation of the research findings
- We used convenience sampling and the number of participants was small though this is appropriate for qualitative designs
- Different methods of data collection were utilized, perspectives were triangulated across key stakeholders and interpretation of the research findings was checked with research participants

Keywords: primary care; learning disabilities, health checks, health inequalities

Word Count: 4000

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Introduction

People with learning disabilities (or intellectual disabilities) experience significant health inequalities, and a higher burden of chronic disease and mortality compared to the general population.[1-3] During the COVID-19 pandemic people with learning disabilities were at increased risk of hospitalization and mortality compared to those without a learning disability.[4] Given health vulnerabilities/inequalities, prioritizing the health needs of people with learning disabilities is crucial [5] and guidance has been developed to address this; in the United Kingdom (UK) recommendations include annual health checks, learning disability registers and reasonable adjustments. [6-8]

Annual health checks can uncover previously unknown conditions, [9] reduce preventable emergency hospitalizations, [10] allow monitoring treatments and foster continuity of care. Templates for annual health checks are available comprising general/specific assessments and they are conducted by General Practitioners (GPs) and practice nurses who facilitate access for people with learning disabilities into healthcare services/systems. [11]

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

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

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cancer screening. [19] Further, while prevalence of long-term conditions in primary care (e.g. epilepsy, diabetes), is higher among people with learning disabilities, best-practice condition-management indicators are lower relative to the general population. [20] Barriers to primary care for people with learning disabilities, include fear, limited carer awareness of health problems, [21] and lack of evidence-based lifestyle interventions (e.g. obesity prevention) combined with systems/organisational barriers to implementation. [22] A review of service user/carer perspectives has identified six facilitators/barriers to people with learning disabilities accessing primary health care including: involvement in healthcare decision-making, time, knowledge/awareness, training, communication and fear/embarrassment. [23] An involved/active role for people with learning disabilities in healthcare interactions is required [24] and UK national guidance recommends primary health teams identify a learning disabilities expert to be a champion, and share good practice. [25]

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

Methods

A qualitative study design was utilized with data collected during focus groups, interviews and surveys; the analytic approach was thematic analysis with an inductive experiential framework informed by stakeholder consultation. Data collection was conducted by the first and second authors (clinical researchers with significant experience in the field of learning disabilities). Data analysis was conducted by the first and last (a clinical academic with significant experience in the field of learning disabilities) authors.

Participants

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Recruitment was purposive to capture a range of stakeholder perspectives. Inclusion criteria were adults (>18 years of age) with mild/moderate learning disabilities with capacity to consent to participate in the research. People with learning disabilities were recruited via a UK regional charity providing support for people with learning disabilities and an online health literacy group. Capacity to consent was assessed by the research team using specialist materials. Accessible study information was distributed to people with learning disabilities accessing the online health literacy group; and by the regional charity who informed the research team of people with learning disabilities who met inclusion criteria and expressed interest in participating. Relatives of adults with learning disabilities were recruited via a regional charity and existing network of contacts who distributed information about the study and researcher contact details.

GPs, practice nurses and sheltered housing managers were recruited through regional general practice and learning disability clinical networks.

Data collection

Data collection was online after completion of informed consent. Two focus groups were conducted with people with learning disabilities. Data collection from relatives was by interview or survey depending on their preference. The focus groups, interviews and surveys followed the same semi-structured format/topic schedule (Online Supplementary materials: OS1). During focus groups and interviews, probes/prompts were used to elicit detail e.g. can you tell me more about that? Key points from the focus groups with people with learning disabilities were summarized by the researcher and read back to the group to check accuracy/comprehensiveness. Interviews with relatives were audio-recorded and transcribed.

Online semi-structured interviews conducted with GPs, nurse practitioners and sheltered housing managers were audio-recorded and transcribed. The interview schedule (OS2)

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comprised five sections: (i) annual health checks (ii) learning disability inclusion tools (iii) barriers to accessing primary care (iv) reasonable adjustments (v) COVID-19.

Patient and Public Involvement

Study documents (consent/information sheets; focus group/interview topic guides) were developed in consultation with a research advisory group led by people with learning disabilities. Feedback included to add content, edit/improve wording for clarity, and create a post-participation debrief document. We consulted GPs regarding the interview topic schedules and received advice on wording/content. Initial review of data indicated that living arrangements/support can impact access to primary care - this was discussed with a GP and informed our decision to recruit sheltered housing managers as participants.

For consultation/dissemination, an online presentation of preliminary findings was made to a research advisory group led by people with learning disabilities. The recommendations were sent to a people with learning disabilities-led advisory group, who made suggestions to improve content/accessibility/readability. Study findings were presented to a GP practice meeting. The local clinical commissioning group, and regional GP clinical practice network advised on dissemination.

Ethical approval was provided by Newcastle University Faculty of Medical Sciences Research Ethics Committee.

Analysis

Thematic analysis was conducted in iterative phases (1) data immersion/familiarisation (2) coding (3) collating/organising data on a coding framework (4) identifying themes (5) reviewing/revising/confirming themes (6) creating definitions of themes/opposing perspectives and identifying illustrative quotes. [26] [27] A model was developed showing theme

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interconnectedness; recommendations were developed informed by thematic analysis findings, research/primary care guidance and consultation with key stakeholders.

In accordance with qualitative analysis best-practice, trustworthiness was ensured by: (i) checking interpretation of findings with research participants (ii) triangulating perspectives/important aspects of the topic by collecting data from different stakeholders using different methods (iii) inviting participants to comment on our summary/interpretation of findings which is important for credibility. [26 27]

Results

Sixteen people participated: comprising 6 people with learning disabilities (2 male; 4 female); four relatives (all female); and eight GPs, practice nurses and supported housing managers (7 female; 1 male). Four themes were identified from the focus groups, interviews and surveys: prioritisation, proactivity, personalisation and prevention; themes and subthemes are shown in Figure 1. The 4 interconnected themes can be applied to different aspects of primary care service provision, this is described throughout the results and shown in Figure 2. The themes informed development of ten recommendations (TR) (Table 1) referred to throughout the results. Quotes are from people with learning disabilities unless stated otherwise; SHM: sheltered housing manager.

The study was conduced during the COVID-19 pandemic and it is important to describe this context to the study and the themes. Participants described changes to healthcare delivery including impacts on health checks: ‘there was a lot of Facetime consultation’ (SHM) and ‘we had to put them (health checks) all on hold’. Some changes were adopted longer-term: ‘Now we’ve got the tech in place it allows patient choice if somebody finds it more comfortable having a consultation by video/phone’. However, this wasn’t suitable in all situations: ‘There are bits of health checks that need to be done face-to-face, you can’t do a breast or testicle check over the phone/video’; and long-term impacts of the pandemic were described ‘It's been

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detrimental to diet/exercise so general health probably has got worse, I’m worried we’re going to have an explosion in diabetes, obesity and frailty in this population over the months ahead’.

(Figure 1 around here)

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

1	*Call them 'yearly' health checks*	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	*Create a supportive practice*	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	*Use a screening tool (learning disability inclusion tool)*	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	*Be pro-active!*	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	*Give a personalised offer around appointments*	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	*In the appointment speak to the person directly*	Even if the person has someone supporting them speak to the person first, it's 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	*Provide easy read information or picture-questionnaires*	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	*Make public health information accessible*	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	*Support with other health services*	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

10	*Have a designated accessibility champion*	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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Theme 1: Prioritisation

This theme describes the rationale and different ways in which people with learning disabilities should/could be prioritized in primary care with regards to access, health needs, and eligibility for annual health checks. Examples included being prioritized on arrival and not being kept waiting with participants valuing being seen promptly 'sometimes the GP will see my daughter on time, this has happened more recently as I've explained about my daughter's inability to wait and her anxiety' (relative). Participants said 'you don't know how long they (the GP) are going to be (it's not always 5-minutes) then you get flustered because the doctor wasn't on time'. The waiting room environment may put people off attending, one participant saying:

> *He doesn't like to go because of how busy it can get...loads of noises... distractions...he has anxiety...if he's making noises and he's aware of people looking at him (SHM)*

The theme highlights the importance of developing cultures within primary care that foster supportive practice and prioritizing healthcare of people with learning disabilities (TR2). Prioritisation comprised two subthemes: co-morbidity/mortality and accurate identification.

Subtheme 1. Co-morbidity/mortality: the rationale for prioritizing people with learning disabilities was their susceptibility to health inequalities plus high co-morbidity and mortality relative to the general population: 'We have patients already at high risk of avoidable illness and preventable mortality, have then another long-term condition to manage which is really difficult and puts them at higher risk of death'.

> *It's really important to develop that culture in the practice that if any of the people on this {learning disability] list are ringing for help they go to the top of the queue. So that's part of the culture that we're trying to develop in our practice to minimize the risk of stuff being missed*

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Another example of prioritizing was allocating time/resources; participants described offering double/longer-appointments to patients with learning disabilities who often have multiple conditions (TR5) and allowing enough time for health checks which vary in quality:

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

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

Theme 2: Proactivity (TR4)

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

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

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example, while participants described seeing the value of health checks e.g. 'they are important and can tell you if things are getting worse' and 'there's no reason I wouldn't want one', one participant with learning disabilities said there was 'no sign saying you are allowed to have a health check, I didn't know I could get one' and a relative said 'health checks have been hit-and-miss'. Further a sheltered housing manager reported that 'sometimes the people we support don't really know what an annual health check is'.

Proactive reaching-out was viewed to be important as people with learning disabilities and carers may not understand the gravity/meaning of symptoms experienced: 'It's hard to know if there are health issues particularly when my son presents with a high pain threshold and is non-speaking/unable to communicate pain/feelings' (relative). A GP said 'unless we provide proactive healthcare to people that otherwise might not present typically we risk their health'. Participants also said that 'people decline them [health checks] and we have to chase around for them'; reasons for this included 'fear of health professionals/settings from past experiences' (relative) or feeling they don't need a health assessment and have no-one to advocate for them:

> *If a person is living independently they may feel they don't want to bother the GP… a lot of people with mild learning disabilities tend not to go to the GP so things can be missed (SHM)*

Methods of reaching-out described by participants included extra phone calls/texts, offering flexibility, information/invitations to attend in different formats, follow-up of non-attenders/those not supported to come to an appointment, and assisting with implementation of follow-up/secondary care arising from primary care visits (TR2 & TR9). Participants described how important reaching-out was for people without an advocate: 'If people don't have wrap-around support they probably fall through the cracks' (SHM).

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Sub-theme 2: Innovation/improvement: This included upskilling/supporting less experienced practices via training/awareness raising, sometimes using a strategic/organisational level approach or facilitated by a learning disability lead (TR10):

> *There was a strategic approach from our CCG to share data monthly about how each practice network was doing with annual health checks, whether they were on target/or not; there was help to practices with poorer uptake.*

Participants described how sharing good practice improves quality: ‘there are various suboptimal [annual health check] templates being used; our CCG has been proactive ensuring everybody uses the national template...we demonstrated how to do annual health checks using the template’. One participant described the importance of a named person supporting strategy implementation e.g. reaching targets: ‘I’m the lead for learning disability...so it’s my responsibility to make sure they’re all done [health checks]’.

Participants described how training can improve skills in primary care: ‘people on reception don’t give you enough time, they rush you and you can make mistakes...if they know you have a learning disability they can talk to you in a different way’ and ‘receptionists should have training to understand challenging behaviour’ (relative). A GP commented that ‘education of staff is really important so they are aware these patients might be phoning up’. However, training may require co-ordination/facilitation: ‘the practice could have a designated lead that everybody recognises as the learning disability doctor/nurse’ (practice nurse) (TR10).

Theme 3. Personalisation (TR2 & TR5)

Participants described the importance of offering a bespoke/personalised service to people with learning disabilities to address some of the things that can make access to primary care difficult. It was viewed as important for a clinician/or reception to know/be on first-name terms with patients with learning disabilities for continuity of care: ‘I know the nurses quite well and that’s

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helpful' and 'seeing the same GP so they get to know you a bit'. Sub-themes included primary care interface problems and reasonable adjustments.

Sub-theme 1. Primary care interface problems: It was evident across all stakeholders that aspects of the primary care interface were challenging/inaccessible to people with learning disabilities e.g. the automated telephone response options when calling the surgery:

> *A patient ringing up with a mild learning disability, might not be able to wait in a phone queue, might struggle with phone numbers...if it says press '1'. Those things haven't been thought about for people with learning disabilities*

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

> *We only book four weeks ahead, if I say I need to see you in six-weeks, they can't book that appointment, so we'll say you need to ring closer to the time; someone who hasn't got a carer, they're probably not going to remember*

Sub-theme 2. Reasonable adjustments: One relative suggested 'ask if the patient needs any reasonable adjustments; what would make the visit easier'. This theme included booking appointments at times that suit the person with learning disabilities and carer/support staff so they could attend with them: 'they could talk for me if I didn't know the answer'. Participants described a lot of people wanting a support person with them however, direct communication from the GP/nurse was viewed important, one participant saying: 'It's important to speak to the person; it's not nice to be talked over the top of' (TR6).

Other examples were provision of accessible information; one participant with learning disabilities suggested avoiding jargon for example: 'They should be called *yearly health checks*...yearly is clearer than annual' (TR1). Other suggestions were providing information beforehand: 'Some people might be frightened' so 'letting people know what to expect at their appointment makes it less scary'. Clear information before/during the appointment and picture-questionnaires were found helpful by people with learning disabilities: 'I liked that I could watch on You-tube what a health check is' and 'you can fill in a form e.g. if you're afraid of needles' (TR7). One participant described receiving a postal questionnaire 'I filled it in with help from my support worker'; people with learning disabilities and GPs/practice nurses reported completing a questionnaire in advance helped prepare for the appointment.

Other pre-annual health check preparations described by participants included texts, videos, picture-questionnaires and phone calls to promote the check and asking when/how it would work best for patients with learning disabilities e.g. was there a particular person they would like to attend with them. A GP described how offering flexibility around health checks improved uptake: 'We went from 49% uptake of annual health checks to 98%'.

However, limitations in reasonable adjustments provision were evident across stakeholders: 'I'm rolling out the idea of it being coded that patients need a reasonable adjustment...when I talk to practices they're not really doing it; it's in their heads but they're not making it visible'. One GP described how staff may lack awareness: 'I think we need to talk about reasonable adjustments in a more accessible way, even for professionals...they've got reasonable adjustments written on their notes that assumes that our staff know what reasonable adjustments are'.

Theme 4: Prevention

This theme related to healthy lifestyles and supporting access to follow-up/secondary care.

Subtheme 1: Healthy lifestyles: Participants described the role of primary care supporting people with learning disability accessing public health campaigns/interventions and healthy

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behaviour/choices e.g. diet/exercise (TR2). Participants described how availability of easy-read public health information can be a valuable resource for prevention:

> *To understand that making health choices around food is really important...people without a learning disability struggle on that...people with a learning disability end-up with diabetes and struggle to manage it (TR 8 & 9)*

While some public health information was found available in accessible formats participants described some gaps and/or comments indicated a lack of awareness of available resources:

> *It would be really helpful to have a website that has all the common health conditions e.g. if you've got asthma I can print something off...there's a lot of medical terminology in the leaflets we give people (TR8)*

Subtheme 2: Supporting access to secondary care: This related to problems with follow-up after health checks including for people who find it hard to reach/or are not brought to the service: *'some people may need a named individual to support them booking appointments or accessing test results and follow-up appointments'* (relative) and '*sometimes they rely on carers to remind them that they have follow-up, I don't necessarily think they would remember'* (sheltered housing manager).

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

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

> *So often there can be identification of a symptom that needs further exploration, then investigations and review and even for somebody without a learning disability that can be quite complex*

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(Figure 2 around here)

Discussion

Four interconnected over-arching themes were identified describing approaches to improve primary care access for people with learning disabilities; the themes map onto dimensions of service provision informing different aspects of primary care and development of ten accessible recommendations. Aligned with previous research, participants emphasized prioritizing people with learning disability in primary care given high prevalence of multiple chronic health conditions, vulnerabilities and mortality. [5] However, participants also described challenges to prioritisation. In common with previous research people were not always correctly coded; GPs being unaware a person has a learning disability is a barrier to implementing appropriate support/adjustments and systems for addressing this require development. [5,12] Prioritisation maps onto to several aspects of service provision – data/coding systems, training and strategy; a strategic proactive approach by a learning disability lead maybe required to instigate/drive systems-level changes e.g. training to facilitate prioritisation. [25] Previous research highlighted training as effective in reducing barriers to primary care for people with learning disabilities. [17] Important areas for training described in our study included identification of people who may not be coded/be incorrectly coded, definitions of/what constitutes reasonable adjustments, and national guidance initiatives. For example, while there is a national health check template it was evident that it is not always utilised; training was seen to facilitate improvement e.g. greater health check uptake.

Previous research highlighted the importance of health checks for preventing treatable conditions being missed; [9,10] and a theme identified in our study was prevention. Initiatives that increased uptake of annual health checks included data collection/sharing, targeted support for practices with poor uptake, methods of identifying people who may be incorrectly coded, proactively reaching-out to patients and offering flexibility. In accordance with research to

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improve comprehensibility of health questionnaires [18] participants valued accessible information received before/during primary healthcare appointments e.g. picture questionnaires especially if people are afraid of attending. [21] Previous research highlighted accessible information is not always available however and needs to be individualised; [14 15] this was reflected in our third theme of personalisation. Participants viewed it important to consider accessibility in broader contexts e.g. embedding relevant Easy-read information into long-term condition management templates and health checks. Participants agreed accessibility of health prevention/public health information/resources, follow-up and secondary care/hospital admissions also require consideration. This requires a primary care culture supportive of people with learning disabilities, and proactive service provision responsive to hard-to-reach patients, that can bridge agencies/providers e.g. a learning disability nurse to liaise with secondary/tertiary care.

Aligned with previous research promoting a more active role for people with learning disabilities in healthcare interactions, [24] participants valued communication directed to the person with learning disability when attending with a supporter. In accordance with previous research it was evident from participants that there were significant barriers across services/systems e.g. barriers to implementation of preventative healthcare [22] and a strategic approach is important to address these; aligned with national guidance a regional learning disability lead can facilitate strategic approaches across practices [25] and this was seen as important by participants (TR10). Designated champions within practices linked to a regional learning disability lead can facilitate ensuring the right support, adjustments and liaison is offered to support people with learning disabilities and families.

A strength of the study is exploring views of three stakeholder groups and using information gathered to build on previous research and develop/co-produce accessible recommendations informed by stakeholder consultation. While data collection was regional, we believe the

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findings will have national and international relevance. A regional inner-city GP practice affirmed utility of the recommendations (saying all seemed practical/could be implemented within practice); and indicated the key to change was a named practice-lead, linked through local primary care networks who could then implement the other recommendations. Future research could explore implementation of the recommendations, and standardised methods/processes of identifying/coding reasonable adjustments.

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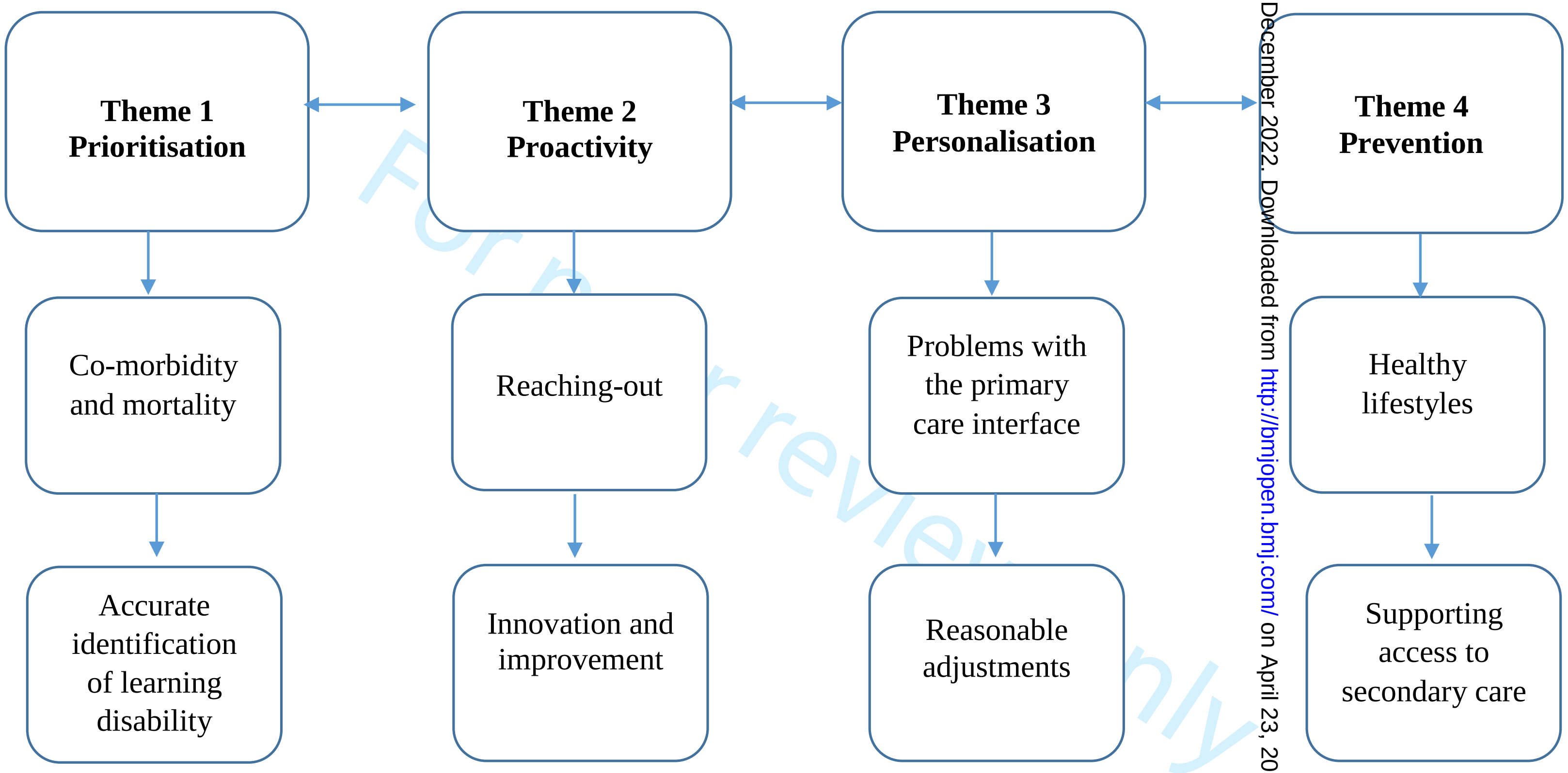

Figure 1 Structure of themes and subthemes

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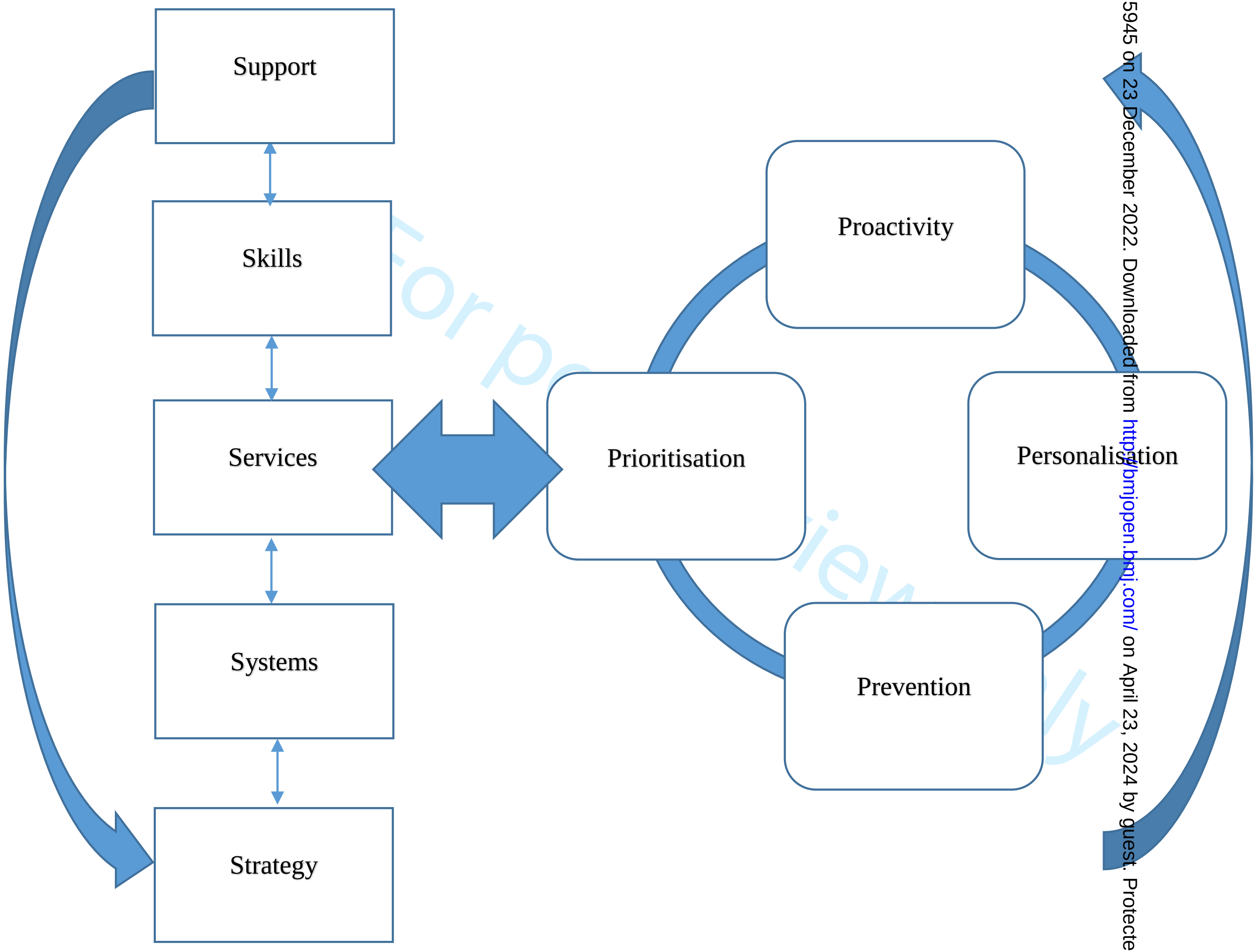

Figure 2 The four themes and their application to different aspects of primary care service provision

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Online Supplementary Materials (OS) 1.

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

At the focus groups, we will talk about health checks. By health checks, we mean going to the doctors or GPs each year to talk about your health and to have some checks done. "It's like a full MOT for the body, to check if you are healthy."

<u>We will ask the following questions in the focus group</u>

Thank you for agreeing to take part in our focus group

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

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

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

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

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

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

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

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

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

Suggestions…

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

- Important
- Necessary
- A waste of time
- Good thing if you're offered them

How have people found health checks/ what are people's expectations and experiences of health checks?

Is there anything that you would like to improve about having your/ your relative's health check?

Any other comments?

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

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Can you think of any reasons why you/ your relative would not want a health check?

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Online Supplementary Materials (OS) 2. Interview Schedule for GPs, nurse practitioners and sheltered housing managers

Part 1. Annual Health checks

- 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?

Part 2. Learning disability inclusion tool – *reported elsewhere*

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

- 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?

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

Part 4. Reasonable adjustments

- 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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- What reasonable adjustments facilitate people with learning disability accessing primary care?

Part 5. COVID-19

- What mitigation is required to be in place in primary care settings for people with learning disability in the context of COVID-19?
- In respect of health checks for people with learning disabilities what have you learned from COVID-19?
- What changes would you incorporate going forwards?
- Is there someone within the surgery provision that could set up or audit people's capacities for phone and online appointments?
- How can people with learning disabilities be supported to accessing the GP more often during COVID-19?

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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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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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needs of people with learning disabilities in primary care. Future research should explore professionals' understanding of reasonable adjustments.

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Article Summary: *Strengths and limitations of this study*

- Qualitative data were collected from 16 key stakeholders (people with learning disabilities, relatives, general practitioners, practice nurses and sheltered housing managers) on ways to improve primary care access for people with learning disabilities.
- Stakeholder consultation informed study design and interpretation of research findings and recommendations were co-developed with people with learning disabilities.
- We used convenience sampling and the number of participants was small though this is appropriate for qualitative designs.
- Different methods of data collection were utilized, perspectives were triangulated across key stakeholders and interpretation of the research findings was checked with research participants.

Keywords: primary care; learning disabilities, health checks, health inequalities

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. [1-3] [4] Given health vulnerabilities, prioritizing the health needs of people with learning disabilities is crucial. [5] Guidance addressing this includes standards of care published in Canada; [6] [7] and United Kingdom (UK) recommendations encompass annual health checks, learning disability registers, reasonable adjustments, and champions to share good practice. [8-10]

Annual health checks can uncover previously unknown conditions, [11] reduce preventable emergency hospitalizations, [12] allow monitoring treatments and foster continuity of care. [7] 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. [13]

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. [14] [15]

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

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best-practice condition-management indicators are lower relative to the general population. [20] In a study examining barriers to improving primary care for people with learning disabilities in Canada, services in which leadership only passively supported innovation were less likely to implement care improvements. [21]

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

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

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

Methods

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

Participants

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

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

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Data collection

Online data were collected using Microsoft Teams after completion of informed consent. An online focus group was conducted with people with learning disabilities and supported by an advocate who facilitated online access. Data collection from relatives was by online interview or survey depending on their preference. The survey comprised the same open-response questions as the interview schedule. During focus groups and interviews, prompts were used to elicit detail, for example: can you tell me more about that? Key points from the focus group with people with learning disabilities were summarized by the researcher and read back to the group to check accuracy. Interviews with relatives were audio-recorded and transcribed. The focus groups, interview and survey topic schedules are shown in the Online Supplementary materials (OS1).

Online semi-structured interviews conducted with GPs, nurse practitioners and sheltered housing managers were audio-recorded and transcribed. The interview schedule (OS2) comprised five sections: annual health checks, learning disability inclusion tools, barriers accessing primary care, reasonable adjustments and COVID-19. Data on inclusion tools is reported elsewhere (McKenzie et al., in review). All participants were sent a debrief email.

Patient and Public Involvement

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

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Analysis

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

Results

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

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

(Figure 1 here)

Theme 1: Prioritisation

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

Subtheme 1: Spaces for people with different needs

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

Subtheme 2. Co-morbidity and mortality

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

Primary care checks were viewed key to identifying preventable health conditions, and important as people with learning disabilities may find it difficult to manage multiple-health conditions: '*We have patients at high risk of avoidable illness and preventable mortality, have another long-term condition to manage, which is really difficult and puts them at higher risk of death' (GP).*

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

Theme 2: Proactivity (R4)

A recurring theme described by participants was the importance of proactively encouraging people with learning disabilities to attend primary care. The theme comprised two subthemes: accurate identification and reaching-out.

Subtheme 1. Accurate identification (R3)

In order to prioritise people, practices need to know which patients have a learning disability: *'we know people with learning disabilities have premature avoidable mortality. The only way we can do something about that is to proactively identify them and bring them in' (GP).* Identification of patients with learning disabilities required the correct diagnostic codes, use of registers, screening, and multi-agency working: '*We need to work together, general practice, paediatrics and hostels*' because *'if you don't have the right code, you don't get the [appropriate] health-care' (GP).*

Subtheme 2: Reaching-out: Participants explained that it was important to reach-out to people with learning disabilities who may be unaware of health service entitlements. While participants with learning disabilities could see the value of health checks: '*they are important, and can tell you if things are getting worse'* and '*there's no reason I wouldn't want one'*, one person with a learning disability said there was '*no sign saying you're allowed a health check, I didn't know I could get one'.* A relative described inconsistent service provision: '*health*

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checks have been hit-and-miss', while a sheltered housing manager said '*sometimes the people we support don't know what an annual health check is'*.

Participants said that '*people decline them [health checks], and we have to chase around for them' (GP).* Reasons included '*fear of health professionals and settings from past experiences*' (relative), or feeling they don't need a health assessment and have no-one to advocate for them: '*If a person is living independently, they may feel they don't want to bother the GP… a lot of people with mild learning disabilities tend not to go to the GP so things can be missed' (SHM).* Participants described the importance of reaching-out to people without an advocate: '*If people don't have wrap-around support, they probably fall through the cracks'* (SHM).

Participants highlighted that people with learning disabilities may have atypical symptoms, and they and carers may not understand symptom significance: '*It's hard to know if there's health issues, when my son is non-speaking and unable to communicate pain or feelings'* (relative). A 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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Subtheme 2: Sharing good practice. Participants described how sharing good practice can improve quality: '*there are various suboptimal [annual health check] templates being used. Our CCG [clinical commissioning group] has been ensuring everybody uses the national template. We demonstrated how to do annual health checks using the template'* (GP). Sharing good practice also included supporting less experienced practices: '*there was a strategic approach from our CCG to share data monthly, about how each practice network was doing with annual health checks, whether they were on target or not. There was help to practices with poorer uptake'*. (GP)

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

Theme 4. Personalisation (R2, R5)

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

Sub-theme 1. Primary care interface problems: It was evident across all stakeholders that the primary care interface was challenging to people with learning disabilities, including automated telephone response options when phoning the surgery: '*A patient ringing-up with a mild learning disability, might not be able to wait in a phone queue, and struggle with phone numbers...if it says press '1'. Those things haven't been thought about for people with learning disabilities' (GP).* A participant with a learning disability said they: *'might not be able to use the check-in machine and put in a date of birth'*. A GP described how: '*We only book four*

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weeks ahead. If I say I need to see you in six-weeks, they can't book that appointment and need to ring closer to the time. Someone who hasn't got a carer, will probably not remember'.

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

Other examples were provision of accessible information and avoiding jargon (R7 and R8); a participant with a learning disability said: '*They should be called yearly health checks...yearly is clearer than annual*' (R1). Clear information before and during appointments was found helpful by people with learning disabilities: '*Some people might be frightened*' so '*letting people know what to expect at their appointment makes it less scary'* and *'I liked that I could watch on You-tube what a health check is'* (R7). A participant with a learning disability described receiving a postal picture-questionnaire and said: '*you can fill in a form, if you're afraid of needles'* and *'I filled it in with help from my support worker'*.

Participants described gaps in awareness of accessible resources: '*It would be really helpful to have a website that has all the common health conditions. If you've got asthma I can print something off. There's a lot of medical terminology in leaflets we give people' (GP)* (R7). Limitations in reasonable adjustments provision was evident, a GP said: *'I'm rolling out the idea of coding that patients need a reasonable adjustment. When I talk to practices they're not really doing it; it's in their heads but they're not making it visible'*. A GP explained staff may lack awareness: *'I think we need to talk about reasonable adjustments in a more accessible*

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way, even for professionals. They've got reasonable adjustments written on their notes; that assumes our staff know what reasonable adjustments are'.

Theme 5: Prevention and Follow-up healthcare

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

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

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

Recommendations informed by the thematic analysis, research, primary care guidance and consultation with key stakeholders, were co-produced with an advisory group led by people 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	*Call them 'yearly' health checks*	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	*Create a supportive practice*	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	*Use a screening tool*	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	*Be proactive!*	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	*Offer personalised appointments*	Ask if the check is a good time for them, and if it is somewhere they can get to. Offer longer appointments so checks are not done in a hurry. Find out what support people might need.
R6	*In the appointment speak to the person directly*	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	*Provide easy-read information or picture-questionnaires*	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	*Make public health and health promotion information accessible*	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	*Support transfer and access to other health services where needed*	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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Discussion

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

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

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training the broader primary care team including receptionists, sharing good practice via demonstrating annual health checks and targeted support for practices, were found effective at increasing health checks and service improvement in this study. UK national guidance [10] highlights the value of learning disability champions, and in this study practitioners with the role were key to driving primary care improvement and innovation, through training, data collection and support for practices less experienced in the care of people with learning disabilities (R10). Important training topics identified in this study included learning disabilities coding, reasonable adjustments, and national guidance initiatives.

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

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

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for people with learning disabilities and families along pathways into secondary or tertiary care. A care co-ordinator or learning disability nurse may be required, for example to support hospital admission, so people with learning disabilities do not get lost to follow-up. In accordance with previous research on preventative healthcare, [23] bridging agencies and providers onwards from primary care requires a proactive organisational-level approach.

A strength of the study is exploring the views of four stakeholder groups, and using the information gathered to co-produce recommendations informed by stakeholder consultation. A regional inner-city GP practice affirmed utility of the recommendations (saying all seemed practical and could be implemented within practice); and indicated the key to change was a named practice-lead, linked through regional primary care networks who could implement the recommendations. The study has a number of limitations; online data collection may have impeded establishing rapport, we collected limited demographic characteristics, and use of convenience sampling in the North East UK may have limited representativeness. At the time of the study primary care services were still being impacted by COVID-19, and under other circumstances, perceptions regarding primary healthcare may have differed. Changes in practice were described including more virtual consultations which in accordance with previous research were found acceptable. [39]

In conclusion all stakeholders highlighted misalignment in the primary care interface with the needs of people with learning disabilities. Improvements in primary care services to best meet the needs of people with learning disabilities continue to be required. The co-produced recommendations can be used immediately, as a complement to existing guidance and as a summary to guide training and service development. Future research should explore standardised methods of identifying and coding reasonable adjustments, and innovation to improve access to the primary care interface, including automated phone and check-in systems. The study findings accord with the crucial role of learning disability leads, providing strategic

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support to prioritize the healthcare needs of people with learning disabilities and drive service improvements and innovation.

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Ethics: Newcastle University Research Ethics Committee gave the study a favourable opinion (Ref: 2102/10380/2020).

Data sharing: Data are available on reasonable request. The data are not publicly available as they contain information that could compromise the privacy of research participants. Some data that support the findings of this study are available on reasonable request from the last author (SH).

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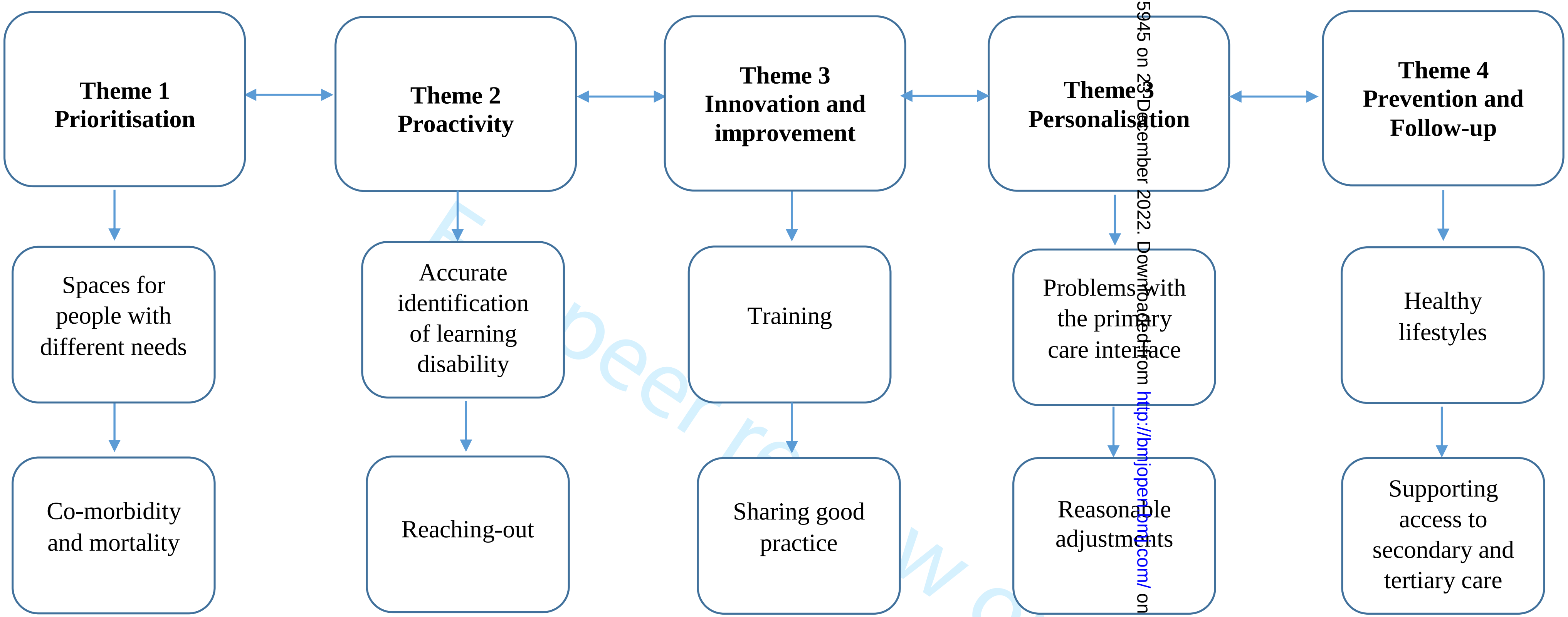

Figure 1 Structure of themes and subthemes

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Online Supplementary Materials 1 (OS1).

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

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

<u>We will ask the following questions in the focus group</u>

Thank you for agreeing to take part in our focus group

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

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

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

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

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

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

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

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

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

Suggestions…

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

- Important
- Necessary
- A waste of time
- Good thing if you’re offered them

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

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

Any other comments?

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

Can you think of any reasons why you/ your relative would not want a health check?

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Online Supplementary Materials 2 (OS2).

Interview Schedule for GPs, nurse practitioners and sheltered housing managers

Part 1. Annual Health checks

- 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?

Part 2. Learning disability inclusion tool – *reported elsewhere*

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

- 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?

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

Part 4. Reasonable adjustments

- 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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- What reasonable adjustments facilitate people with learning disability accessing primary care?

Part 5. COVID-19

- What mitigation is required to be in place in primary care settings for people with learning disability in the context of COVID-19?
- In respect of health checks for people with learning disabilities what have you learned from COVID-19?
- What changes would you incorporate going forwards?
- Is there someone within the surgery provision that could set up or audit people's capacities for phone and online appointments?
- How can people with learning disabilities be supported to accessing the GP more often 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

Title - 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	Page 1/line 3
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2/ line 34

Introduction

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

Methods

Qualitative approach and research paradigm - 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**	Line 125-127
Researcher characteristics and reflexivity - 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	Line 167-169
Context - Setting/site and salient contextual factors; rationale**	Line 130-141
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Line 130-141
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Line 127-128 and 132-138
Data collection methods - 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**	Line 125-126 Line 143-154

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Data collection instruments and technologies - 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
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Line 180-184
Data processing - 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
Data analysis - 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
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Line 174-178

Results/findings

Synthesis and interpretation - 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
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Line 179-337

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - 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
Limitations - Trustworthiness and limitations of findings	Line 400-404

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Line 435
Funding - 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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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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needs of people with learning disabilities in primary care. Future research should explore professionals' understanding of reasonable adjustments.

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Article Summary: *Strengths and limitations of this study*

- Qualitative data were collected from 16 key stakeholders (people with learning disabilities, relatives, general practitioners, practice nurses and sheltered housing managers) on ways to improve primary care access for people with learning disabilities.
- Stakeholder consultation informed study design and interpretation of research findings and recommendations were co-developed with people with learning disabilities.
- We used convenience sampling and the number of participants was small though this is appropriate for qualitative designs.
- Different methods of data collection were utilized, perspectives were triangulated across key stakeholders and interpretation of the research findings was checked with research participants.

Keywords: primary care; learning disabilities, health checks, health inequalities

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. [1-3] [4] Given these health vulnerabilities, prioritizing the health needs of people with learning disabilities is crucial. [5] Guidance addressing this includes standards of care published in Canada; [6] [7] and United Kingdom (UK) recommendations encompass annual health checks, learning disability registers, reasonable adjustments, and champions to share good practice. [8-10]

Annual health checks can uncover previously unknown conditions, [11] reduce preventable emergency hospitalizations, [12] allow monitoring treatments and foster continuity of care. [7] 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. [13]

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 cannot gain access to appropriate healthcare and adjustments. Methods of identifying people with learning disabilities in primary care are required. [14] [15]

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

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best-practice condition-management indicators are lower relative to the general population. [20] In a study examining barriers to improving primary care for people with learning disabilities in Canada, services in which leadership only passively supported innovation were less likely to implement care improvements. [21]

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

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

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

Methods

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

Participants

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

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

Data collection

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

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with people with learning disabilities were summarized by the researcher and read back to the group to check accuracy. Interviews with relatives were audio-recorded and transcribed. The focus groups, interview and survey topic schedules are shown in the Online Supplementary materials (OS1).

Online semi-structured interviews conducted with GPs, nurse practitioners and sheltered housing managers were audio-recorded and transcribed. The interview schedule (OS2) comprised five sections: annual health checks, learning disability inclusion tools, barriers accessing primary care, reasonable adjustments and COVID-19. Data on inclusion tools is reported elsewhere. [37] All participants were sent a debrief email.

Patient and Public Involvement

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

Analysis

Thematic analysis was conducted manually by the first and last authors (an experienced clinician and researcher in the field of learning disabilities) in iterative phases following anonymization: (1) data familiarisation (2) coding (3) developing a coding framework (4) identifying themes (5) reviewing, revising and confirming themes and definitions (6) and identifying illustrative quotes. [38] [39] Informed by thematic analysis findings, research, primary

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care guidance and consultation with key stakeholders, recommendations were co-produced with people with learning disabilities (Table 1). In accordance with qualitative analysis best-practice, trustworthiness was ensured by: checking interpretation of findings with participants, triangulating perspectives and important aspects of the topic by collecting data from different stakeholders using different methods, and by inviting participants to comment on a summary of findings. [38 39]

Results

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

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

(Figure 1 here)

Theme 1: Prioritisation

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This theme described the rationale for prioritizing people with learning disabilities in primary care, and how to support this (Recommendation: R2), and comprised two subthemes: spaces for people with different needs, and co-morbidity and mortality.

Subtheme 1: Spaces for people with different needs

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

Subtheme 2. Co-morbidity and mortality

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

Primary care checks were viewed key to identifying preventable health conditions, and important as people with learning disabilities may find it difficult to manage multiple-health conditions: '*We have patients at high risk of avoidable illness and preventable mortality, have another long-term condition to manage, which is really difficult and puts them at higher risk of death' (GP).*

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

Theme 2: Proactivity (R4)

A recurring theme described by participants was the importance of proactively encouraging people with learning disabilities to attend primary care. The theme comprised two subthemes: accurate identification and reaching-out.

Subtheme 1. Accurate identification (R3)

In order to prioritise people, practices need to know which patients have a learning disability: *'we know people with learning disabilities have premature avoidable mortality. The only way we can do something about that is to proactively identify them and bring them in' (GP).* Identification of patients with learning disabilities required the correct diagnostic codes, use of registers, screening, and multi-agency working: '*We need to work together, general practice, paediatrics and hostels*' because *'if you don't have the right code, you don't get the [appropriate] health-care' (GP).*

Subtheme 2: Reaching-out: Participants explained that it was important to reach-out to people with learning disabilities who may be unaware of health service entitlements. While participants with learning disabilities could see the value of health checks: '*they are important, and can tell you if things are getting worse'* and '*there's no reason I wouldn't want one'*, one person with a learning disability said there was '*no sign saying you're allowed a health check, I didn't know I could get one'*. A relative described inconsistent service provision: '*health*

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checks have been hit-and-miss', while a sheltered housing manager said '*sometimes the people we support don't know what an annual health check is'*.

Participants said that '*people decline them [health checks], and we have to chase around for them' (GP).* Reasons included '*fear of health professionals and settings from past experiences*' (relative), or feeling they don't need a health assessment and have no-one to advocate for them: '*If a person is living independently, they may feel they don't want to bother the GP… a lot of people with mild learning disabilities tend not to go to the GP so things can be missed' (SHM).* Participants described the importance of reaching-out to people without an advocate: '*If people don't have wrap-around support, they probably fall through the cracks'* (SHM).

Participants highlighted that people with learning disabilities may have atypical symptoms, and they and carers may not understand symptom significance: '*It's hard to know if there's health issues, when my son is non-speaking and unable to communicate pain or feelings'* (relative). A 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

Theme 3 focussed on service development and comprised two subthemes: training and sharing good practice.

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

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suggested training on behaviours viewed as challenging would be helpful: '*receptionists should have training to understand'*.

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

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

Theme 4. Personalisation (R2, R5)

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

Sub-theme 1. Primary care interface problems: It was evident across all stakeholders that the primary care interface was challenging to people with learning disabilities, including automated telephone response options when phoning the surgery: '*A patient ringing-up with a mild learning disability, might not be able to wait in a phone queue, and struggle with phone numbers…if it says press '1'. Those things haven't been thought about for people with learning*

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

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

Other examples were provision of accessible information and avoiding jargon (R7 and R8); a participant with a learning disability said: '*They should be called yearly health checks...yearly is clearer than annual*' (R1). Clear information before and during appointments was found helpful by people with learning disabilities: '*Some people might be frightened*' so '*letting people know what to expect at their appointment makes it less scary'* and *'I liked that I could watch on You-tube what a health check is'* (R7). A participant with a learning disability described receiving a postal picture-questionnaire and said: '*you can fill in a form, if you're afraid of needles'* and *'I filled it in with help from my support worker'.*

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

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

Theme 5: Prevention and Follow-up healthcare

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

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

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

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Recommendations informed by the thematic analysis, research, primary care guidance and consultation with key stakeholders, were co-produced with an advisory group led by people 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	*Call them 'yearly' health checks*	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	*Create a supportive practice*	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	*Use a screening tool*	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	*Be proactive!*	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	*Offer personalised appointments*	Ask if the check is a good time for them, and if it is somewhere they can get to. Offer longer appointments so checks are not done in a hurry. Find out what support people might need.
R6	*In the appointment speak to the person directly*	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	*Provide easy-read information or picture-questionnaires*	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	*Make public health and health promotion information accessible*	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	*Support transfer and access to other health services where needed*	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.

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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Discussion

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

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

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training the broader primary care team including receptionists, sharing good practice via demonstrating annual health checks and targeted support for practices, were found to contribute to increasing health checks and service improvement in this study. UK national guidance [10] highlights the value of learning disability champions, and in this study practitioners with the role were key to driving primary care improvement and innovation, through training, data collection and support for practices less experienced in the care of people with learning disabilities (R10). Important training topics identified in this study included learning disabilities coding, reasonable adjustments, and national guidance initiatives.

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

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

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for people with learning disabilities and families along pathways into secondary or tertiary care. A care co-ordinator or learning disability nurse may be required, for example to support hospital admission, so people with learning disabilities do not get lost to follow-up. In accordance with previous research on preventative healthcare, [23] bridging agencies and providers onwards from primary care requires a proactive organisational-level approach.

A strength of the study is exploring the views of four stakeholder groups, and using the information gathered to co-produce recommendations informed by stakeholder consultation. A regional inner-city GP practice affirmed utility of the recommendations (saying all seemed practical and could be implemented within practice); and indicated the key to change was a named practice-lead, linked through regional primary care networks who could implement the recommendations. The study has a number of limitations; online data collection may have impeded establishing rapport, we collected limited demographic characteristics, and use of convenience sampling in the North East UK may have limited representativeness. At the time of the study primary care services were still being impacted by COVID-19, and under other circumstances, perceptions regarding primary healthcare may have differed. Changes in practice were described including more virtual consultations; in accordance with previous research this format for consultation was found acceptable. [40]

In conclusion all stakeholders highlighted misalignment in the primary care interface with the needs of people with learning disabilities. Improvements in primary care services to best meet the needs of people with learning disabilities continue to be required. The co-produced recommendations can be used immediately, as a complement to existing guidance and as a summary to guide training and service development. Future research should explore standardised methods of identifying and coding reasonable adjustments, and innovation to improve access to the primary care interface, including automated phone and check-in systems. The study findings accord with the crucial role of learning disability leads, providing strategic

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support to prioritize the healthcare needs of people with learning disabilities and drive service improvements and innovation.

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Ethics: Newcastle University Research Ethics Committee gave the study a favourable opinion (Ref: 2102/10380/2020).

Data sharing: Data are available on reasonable request. The data are not publicly available as they contain information that could compromise the privacy of research participants. Some data that support the findings of this study are available on reasonable request from the last author (SH).

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Figure 1. Structure of themes and subthemes

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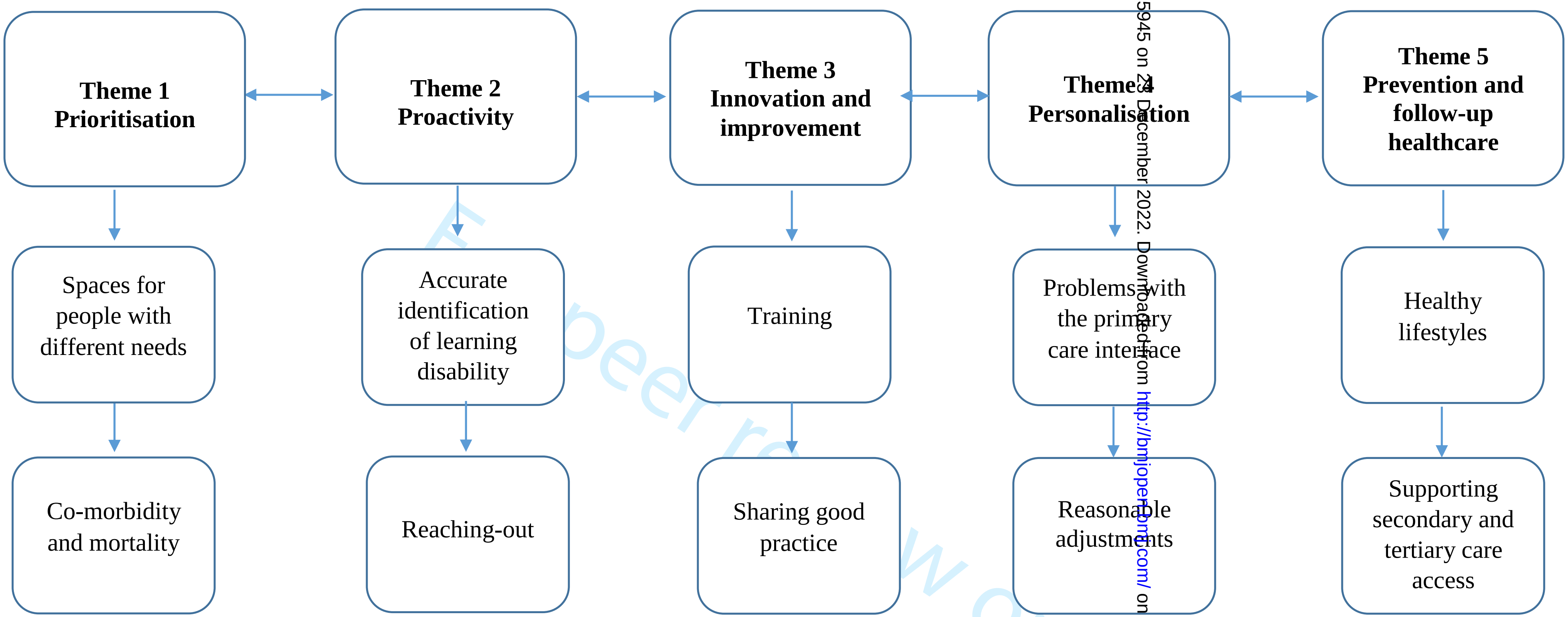

Figure 1 Structure of themes and subthemes

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Online Supplementary Materials 1 (OS1).

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

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

<u>We will ask the following questions in the focus group</u>

Thank you for agreeing to take part in our focus group

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

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

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

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

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

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

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

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

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

Suggestions…

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

- Important
- Necessary
- A waste of time
- Good thing if you’re offered them

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

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

Any other comments?

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

Can you think of any reasons why you/ your relative would not want a health check?

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Online Supplementary Materials 2 (OS2).

Interview Schedule for GPs, nurse practitioners and sheltered housing managers

Part 1. Annual Health checks

- 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?

Part 2. Learning disability inclusion tool – *reported elsewhere*

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

- 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?

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

Part 4. Reasonable adjustments

- 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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- What reasonable adjustments facilitate people with learning disability accessing primary care?

Part 5. COVID-19

- What mitigation is required to be in place in primary care settings for people with learning disability in the context of COVID-19?
- In respect of health checks for people with learning disabilities what have you learned from COVID-19?
- What changes would you incorporate going forwards?
- Is there someone within the surgery provision that could set up or audit people's capacities for phone and online appointments?
- How can people with learning disabilities be supported to accessing the GP more often 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

Title - 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	Page 1/line 3
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2/ line 34

Introduction

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

Methods

Qualitative approach and research paradigm - 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**	Line 125-127
Researcher characteristics and reflexivity - 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	Line 167-169
Context - Setting/site and salient contextual factors; rationale**	Line 130-141
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Line 130-141
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Line 127-128 and 132-138
Data collection methods - 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**	Line 125-126 Line 143-154

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Data collection instruments and technologies - 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
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Line 180-184
Data processing - 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
Data analysis - 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
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Line 174-178

Results/findings

Synthesis and interpretation - 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
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Line 179-337

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - 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
Limitations - Trustworthiness and limitations of findings	Line 400-404

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Line 435
Funding - 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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