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Sunderland**

McShea, Lynzee, Giles, Karen, Murphy, A and Ling, Jonathan  
(2021) An alternative approach for detecting hearing loss in  
adults with learning disabilities. British Journal of Learning  
Disabilities. ISSN 1354-4187

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## **Accessible summary**

People with learning disabilities, like everyone else, need to have their health checked but this can sometimes be difficult.

We asked people with learning disabilities and the people who look after them what they thought about how they have blood tests done or their hearing checked.

We found out the things that make it a positive experience.

We learnt that people learning disabilities and the people who look after them with thought point of care testing would be a good idea

We learnt what things they thought should be put in place to make this type of testing work well for them.

## **Title**

Can point of care testing improve access to diagnostic screening and testing for people with learning disabilities? Exploring perspectives to improve access and equity.

## **Running Head**

POCT: Exploring perspectives for diagnostic access

## **Key Words**

Learning disabilities, equity, point of care testing, workforce, health screening

## **Abstract**

**Background:** People with learning disabilities have an increased risk of diabetes, cardiovascular disease and hearing loss. This study explored service users and health professionals' perspectives and experiences of adopting minimally invasive diagnostic and screening devices, known as point of care testing (POCT) as a means of improving access and engagement.

**Materials and Method:** Focus groups and semi-structured interviews were undertaken with attendees at a non-healthcare day centre, specialist learning disability clinical network and national leads as well as researchers into learning disability and point of care issues. Thematic analysis of the data was undertaken.

**Results:** There was a lack of awareness and experience of POCT across the users and health professionals. Despite this, on seeing the devices and discussing application there was strong support and acceptability across all participants for their use so long as individual needs were addressed. There was no consistent sense of where this testing should be done but support for the flexibility this could provide in terms of non-medicalised locations and individual needs. Strategies for success included the use of specific adjustments such as the presence of a known carer, pre-testing information in an appropriate format and taking into account each individual's preferences.

Conclusions: POCT is considered a viable and useful method for improving access to testing for people with learning disabilities. Adoption barriers in implementation identified as specific to the field of learning disabilities included lack of POCT awareness, diagnostic overshadowing concerns and adjusting for individualised needs is essential.

## 1 Introduction

Learning disability has a significant and well-documented impact on health and well-being. People with learning disability have a significantly decreased life expectancy compared to the general population. Premature deaths are 42% higher for this population. Risk and incidence of a range of diseases and health conditions is higher than the general population, including diabetes, hearing loss and to a lesser degree, cardiovascular disease. Obesity, a known risk factor for diabetes, is higher in the learning disability population with 22.3% having a Body Mass Index over 30 compared to 9.7% in the general population.

People with learning disabilities are defined as a vulnerable client group, less likely to access healthcare (RCGP 2010) and there are known concerns regarding equity of access to health care assessment and treatment. Other reports and research reinforces this and the evidence of 'diagnostic overshadowing' being prevalent, incorrectly attributing signs, symptoms or behaviour to an individual's learning disability, further compounds this inequity impacting on care received, health outcomes and avoidable harm being an issue that is of concern within this client group.

### 1.1 Learning Disability Health Checks and access

The Learning Disability Annual Health Check was introduced in the UK following a series of reports and recommendations following ongoing concerns about health inequalities and is one of the measures adopted to try to improve identification and subsequent access and management of key health risks for people with learning disability (Valuing People 2002, Michaels 2008, XX). The annual health check for people with a learning disability, unlike the general population health check, is a Direct Enhanced Service (DES) (NHS England 2019). GPs are required to provide this for all individuals, registered with their practice as having a learning disability and who are over 14 years old. It attracts a tariff payment and uptake activity is monitored by Clinical Commissioning Groups (CCGs). The health check has a number of elements (NHS England 2017) which include functional assessments, sexual health, cancer screening, and a baseline assessment which includes health promotion elements, vision and hearing assessments. It includes a 'body system' based general assessment, the breadth of which is completed at the discretion of the primary care practitioner informed by the presenting individual's health status or medication monitoring requirements. Laboratory investigations are outlined on a 'clinically relevant' basis with some prompts for specific aspects such as thyroid testing. An outcome of the annual check process is the creation of a Health Action Plan and this is a requirement of the DES contract.

There is evidence that health checks have led to the identification of previously unmet health needs (PHE 2014) and thus have a role in addressing health inequality and access. There have however, been a number of issues and concerns about the health check (PHE 2014), mainly in relation to uptake and access. The learning disability

population historically have had poor uptake of these health checks with average uptake across the UK of 43.2% in 2014/5 (NHS Digital 2016). As well as concerns about uptake of the checks, Robertson (2015) identified the main barriers experienced for people with a learning disability in accessing health services relate to process issues. These included waiting times, accessibility and lack of reasonable adjustments. Whilst some examples exist of initiatives to improve uptake and quality of health checks (Turner et al 2012, Challinor 2017), Robertson (2015) identified a lack of published research into initiatives to address these issues, and the potential for improvement and development in the delivery of the health check.

Bent et al (2015), McShea (2015) also identified a specific issue about the assessment of hearing loss within the health check. Despite hearing loss having a greater prevalence within the learning disability population, estimated at 40 % (Carvill 2001) and it being included in the health check process, detection rates remain low. They identified a lack of awareness and training in relation to audiology, how to complete a hearing assessment and a reluctance to refer to specialized services by practice nurses and GPs. Bent et al (2015) identified the impact of identification of hearing loss in several individuals and how this had a significant positive impact including examples of a reduction in the level of support required through identifying and treating hearing loss.

The annual health check was designed as a means to address inequality in health assessment and treatment, and when accessed, can identify health need, but whilst it still appears to experience barriers there exists a need to seek and test out options to improve access and engagement.

## 1.2 Point of Care Testing

Alongside national and local initiatives in health promotion and reduce the impact of significant health risk factors, there has been a focus on technology adoption in healthcare (FYFV). One area of development is improving access to laboratory and physiological screening and diagnostics through maximizing available and emerging technology (Carter 20XX). Point of care testing (POCT) is the ability to undertake laboratory tests (biochemistry, haematology or molecular-based) near or at the point of the patient. POCT is not a new concept in healthcare, but the emerging technologies and greater miniaturization are enabling an increased range of testing (Luppa et al 2016) and further reducing the invasiveness of sample collection, and reducing the complexity for users in undertaking the testing. Documented POCT benefits include faster clinical decision making, affecting length of stay and improving self-care management, for example through better glycemic control (Fink et al 2014, Leman et al 2004). POCT technology is available for other diagnostic or screening including hearing loss assessment and atrial fibrillation and can be used by non-scientists. POCT uses minimally invasive approaches to sampling often requiring only a capillary (finger prick) sample or very small venous sample. Hearing screening is undertaken through a passive tool, similar to an in-ear headphone. POCT devices are also quite small and mobile and can be used outside a traditional clinical setting. POCT is recommended for

use within the general health check process predominately for lipids (ref) though uptake is variable. POCT is yet to be fully embedded into wider UK healthcare settings and some common barriers identified for adoption include cost benefit concerns, accuracy of results and managing the quality assurance requirements, particularly in primary care settings (Jones 2013, Quinn et al 2015).

Guidelines for the annual health check are available for conducting the checks and were reviewed in 2017 (RCGP 2017) and POCT is now referred to as an option in obtaining blood samples, but with minimal information on practical use for people with a learning disability.

### *1.3 Learning Disability and POCT: The Current Study*

In addition to the identified issues of health inequity and the challenge of addressing uptake of checks, some people with learning disabilities are known to experience anxiety regarding health interventions. This includes participating in diagnostic or screening processes, attending hospital or clinical settings, requiring reasonable adjustments to be identified and implemented. Many of the existing studies exploring solutions to this are single case studies Cavalari (2013), Kenney et al (2014) and focus on the use of desensitisation approaches to minimize anxiety experienced during clinical interventions.

It was considered that POCT could have the potential to provide an opportunity to improve both access to diagnostics and screening and potentially the user experience. The use of a minimally invasive intervention could reduce risks and potential for harm for individuals. POCT could afford flexibility in where and how elements of the current health check are undertaken and accessed. There are a few qualitative studies concerned with factors affecting adoption of POCT in Primary and Secondary care settings (Jones 2013) but no identified literature on POCT in relation to learning disabilities and its potential role to improve access and engagement and the experience and use of POCT for people with a learning disability. The studies POCT have not explored whether this would be acceptable or viable from either a service user or clinician perspective for people with a learning disability.

## 2 Research question

The study addressed the following research questions:

What are the experiences and perspectives of service users, carers and practitioners with regard to the acceptability of using POCT for people with a learning disability?

How could this inform future development/adoption in practice?

### 3 Design

The study was undertaken using a qualitative, evaluative approach to gain understanding of the use and acceptability of POCT for people with a learning disability. Evaluation is a key tool in facilitating the translation of knowledge into practice. A qualitative study was identified as the most appropriate approach to the question being explored (Brophy, Snooks & Griffiths, 2008) for several reasons. Primarily this was used as there was a need to gain insight into the area due to the paucity of evidence on the use of POCT for people with a learning disability and an appropriate approach for exploratory studies and where little is known (Braun & Clark 2013). This approach was also used as it was considered that the primary data collection tools of focus groups and semi structured interviews would be more beneficial to the service users in respect of enabling them to share their experiences and perspectives in a safe, supported and accessible way (Frith 2000).

#### 3.1 Sampling

Stakeholder groups were people with a recognised learning disability (service users), specialist leads (Clinical Commissioning Group, NHS England, learning disability national leads) and clinicians (GPs with special interest in learning disability, learning disability liaison nurses and community learning disability nurses).

Service users were recruited by convenience sampling from attendees at a learning disability day service facility ( $n$  10). A member of staff from the day service initially approached service users to tell them more about the study and the opportunity to be part of a small discussion group about their experiences of health checks and screening tests. They were also present during the focus group activity. All individuals were identified as having capacity to consent by the service and provided with information and explanations adjusted to their needs and informed consent was obtained immediately prior to the running of the focus groups. The researcher had capacity assessment training.

Practitioner stakeholders ( $n$  22) were recruited by purposive sampling using a specialist network. For all participants, written informed consent was obtained by the researcher at the beginning of each focus group. A number of national leads in audiology, laboratory services and learning disability nursing participated in semi structured telephone interviews. Participant information sheets and consent forms were distributed prior to the telephone interview and consent obtained at the start of the call.

#### 3.2 Procedure

Data collection took place via two service user focus groups (five participants in each), five semi structured, qualitative telephone interviews, with national leads/specialist researchers and three focus groups with Learning Disability Specialist Nurses, GPs and Commissioners within the North East of England. The national leads were from POCT/pathology services, Learning Disability Nursing, senior Audiologist with a special

interest in learning disability, a regional Network Lead for Learning Disability and a specialist health promotion learning disability nurse with a geographical lead role in improving the quality of the annual health check.

Data were collected between October 2016 and March 2017. Some examples of point of care machines (actual and pictorial representations) were used within the focus group discussions as part of the aim to explore experiences and familiarity with devices. The ones selected for this purpose were ones most likely to have been encountered with having had routine blood sampling including blood glucose, cholesterol and also a hearing screening device. In addition, for the service user focus groups, the facilitator used a 'role play' approach to provide an example of someone having a health check and being asked questions by the doctor. This approach was used to support individuals and reduce any anxiety that may have occurred as a result of the focus group setting and facilitate recall and discussion of their experiences.

All interviews were recorded and transcribed verbatim, with all personal and identifiable information being removed at the point of transcription. Digital and audio files were deleted at verification of the transcript by the researcher. Transcripts of interviews were secured securely in accordance with University policy and procedures. Data analysis was conducted using Framework analysis (Ritchie & Spencer 1994). Following a period of review and immersion within the data, initial themes were identified separately and then cross referenced/mapped across the data by the lead researcher. The final stage of the analysis involved a second researcher reviewing the data and themes and exploring associations, meanings and providing explanations. Regular meetings of the researchers facilitated further reduction and development of the themes. Ethical review and approval was granted by the research ethics committee of the University of the first author.

## 4 Results

Thematic analysis resulted in four themes:

- Awareness of point of care testing
- Acceptability
- Essential strategies for making it work
- Culture shift

### *4.1 Awareness of point of care testing*

All participants across the stakeholder groups (with the exception of laboratory and audiology specialists), had little or no awareness of point of care devices, with only two service user participants having experienced finger prick testing or reported seeing a relative use one for diabetes management.

Service users had awareness of blood pressure machines and having blood taken but little or no experience of point of care devices, though some had seen relatives with machines for monitoring diabetes at home.

Those who had seen or experienced similar equipment were observed not to appear worried by the demonstration in comparison to others who had not seen it before. Those who had had previous experience of the test reported not being averse to it; it seemed that knowing what was going to happen had helped them.

*R 2: I've had it done once at the doctors.*

*I 1: Was it your general health check?*

*R 2: Yeah.*

*I 1: And did they explain you were going to have that blood test?*

*R 2: Yeah, uh-huh.*

*I 1: And what did you think of it when you had it?*

*R 2: It was alright. I wasn't even bothered about it.*

*(FG2, p32-33)*

Commissioner and clinician participants tell stories of carers as well as clinicians being unaware of testing by POCT or being unaware of the importance of screening tests.

*I've never really heard of point of care in, like, what equipment is out there, really. You know, the things you were describing before – that would be really good and useful. But we've not really come across it before to be fair*

*(Learning Disability Hospital Liaison Nurse FG1)*

*As a community learning disability nurse, I've had very little experience of point of access of what you're talking about.*

*(Community Learning Disability Nurse FG 1)*

Audiology based point of care devices had a very low awareness across all groups and the wider issue of hearing screening awareness and its importance was raised:

*It's about showing people what the consequences are. And it's just something that's not often seen. I mean, even in the general population - how many people have their eyes tested? Probably everyone. How many people had their hearing testing? It's just not... Not noticed in the same way. Until you can provide the evidence or give people the success stories. And I think that's the key for this.*

*(S2 interview)*

Learning disability nurses work in a range of roles and settings, often not specifically health or acute care environments and their exposure and limited experience of the equipment as well as undertaking clinical skills was raised.

*I reckon in terms of training when... When if you're a student, like a learning disability nurse student, you don't get trained in all these clinical... You don't get any training. We're allowed to observe them, but it's not like one of our competencies is to actually do it. So we just observe someone else doing it until they think that we're competent enough. So maybe if it was introduced to the university at the offset. So that the students feel comfortable doing it, so that they know what it's all about. I even know about the diagnostic thing.*

*Because we... We miss out on that big time, I think. As learning disability nurses, compared to the general nurses. We just don't get the opportunity.*  
(Learning Disability Nurse FG 3)

#### 4.2 Acceptability

The potential contribution of using POCT to the management of anxiety and needle phobia emerged, with POCT being welcomed as something that could be used as an alternative to current methods and be less stressful. There was some anxiety and changes in non-verbal behaviour expressed by some service users in the focus group who were not familiar with the equipment, in particular on seeing the lancets for the first time (despite their being no visible needle). Feeling nervous and not knowing what was going to happen were things that were mentioned by those who were able to verbalise their feelings about having diagnostic tests.

Service users described what had worked well in their experiences of needle procedures and this was characterised by it being important to have been prepared in knowing what to expect and being well prepared in advance of their tests. These experiences were primarily related to dental care.

Service users and clinicians identified the importance of first or previous experiences of needles and testing as impacting on acceptability.

Responses were positive to the devices and the testing method being used in practice and supported as being potentially easier to do, and less stressful for patients and staff as well as the technology enabling improved access to testing and interventions for individuals.

*"I3: You said you wished your doctor had those?"*

*R3: Aye"*

*(FG2. p.33)*

*Well, it will mean that some people who can't currently get tested for whatever, will get tested. And that's the most important thing in all this*

*(GP FG3IG)*

*This guy won't even sit still to be examined. So... so this potentially offers a huge solution to that doesn't it? If there is something less invasive, and that gives us the answers we need*

*(Specialist GP FG2NH)*

The issue of POCT being something to help provide solutions and potentially improve timely access and reduce delays was valued and identified by the participants, particularly the clinicians, as a positive benefit in relation to their roles and some of the interventions they are asked to do in supporting people with learning disabilities.

*I do think, though, if there were easier ways, they would use it. Definitely. You know, they'll come to us and say 'have you got any ideas how we can do this*

*(Liaison Nurse)*

*I think the big thing that we probably all face is...is kind of, the delays in diagnostics for whatever reason...it's the delay in time of working all of that out and getting all of the reasonable adjustments in place....so where were talking, you know, about diagnostics being smarter and more effective,....that's the issue*

*(Learning disability nurse)*

Areas of caution about acceptability related to clinical decision making were identified. Whilst benefits were expressed by clinicians of POCT in respect of access, speed of results and reduction in appointment times, two areas of concern emerged. One was clinical decision-making based on a POCT- obtained result. This included understanding what tests were available via POCT and ensuring sufficiency of information from results to make a decision (devices shown were single test and capillary based). The concerns also included whether the information obtained would assist in the decision-making.

*That's good if I've got some information about some people I never had before, but it's not actually shifting what I can do for somebody*

*(GP Special Interest in learning disability)*

Some practitioner focus group participants highlighted concerns that a test is only worth putting the person through if a clinical decision can be made to provide help for that person. Also providing initial access may in itself bring other issues was identified as an issue to consider:

*You're having to end up with an idea that they've potentially got a condition. But we cannot treat it because of the absence of further testing, and non-invasive testing. Absolutely.*

*(Commissioner/Learning disabilities nurse)*

Other cautions in respect of acceptability were practical issues pertaining to cost and cost effectiveness of point of care versus laboratory-based testing and the wider health benefit. There was the hope that *'the health economics argument will make the case'* (Community Liaison Nurse).

There were also potential benefits identified specific to this population and current practice:

*...I'm interested in, kind of, what you were saying about how much the equipment is [costs]. And actually, versus how much the other process, and the length, and the amount of practitioners involved, versus that amount it will be. Because we've had district nurses involved for months with people trying to get bloods [because of frequent refusals], which is a long time*

*(Learning disability nurse)*

Issues about frequency of use, maintenance and data management were identified as factors that need to be taken into consideration.

#### *4.3 Strategies for making it work*

Across all participant groups, the need for ensuring adjustment and adaptation of using POCT for individuals with a learning disability emerged. A number of approaches and essential elements emerged as factors for success in implementation.

These strategies were concerned with communication, engagement and individualisation, and included suggestions that had come from experiences that had been effective from both service users and practitioners' perspectives. Strategies perceived to work during health check consultations and needle procedures were identified by all participants and included the need for appropriate information, preparation and support.

Managing expectations, individualised and age appropriate information prior to the testing was a key area identified as a strategy for making this accessible and a positive experience. For service users this specifically included having clear explanations about POCT, what the equipment does and what will happen to them during the test.

*Interviewer1: Is there anything that stop you wanting to go to your health check?*

*Respondent 4: Just....explain it [the health check] a bit more to me*

*Interviewer1: Before you go [to the doctors]?*

*R4: Yeah*

*Interviewer 2: [After a demonstration of capillary testing kit] and what about getting a sample taken out of your arm with a needle like this? Does that worry you?*

*Respondent 4: No*

*Interviewer 2: That doesn't worry you either?*

*Respondent 4: because you've explained.*

*(Service User)*

The importance of demonstrating devices beforehand was raised and then explored further with service users. We found that services users had a range of reactions on first seeing equipment, although they began to relax and became more engaged after the initial viewing and handling of the equipment. This suggests value in including a pre-testing preparation period in advance of having tests undertaken.

*So the communication and how we show people, you know, how we let people have a look at it. Play with it, try it, look at it. You know, touch it. All of that. How*

*we present it to people and introduce it to people and families, and paid staff, I think will be the... the make or break of the project.*

*(Specialist lead)*

Another key strategy for success was support through the process. Service users identified either having a carer present, or a known carer or clinician involved as helpful to them. On the whole having a family member present was considered to be important in reducing anxiety and help with stress management though it was also identified as a possible barrier in some instances.

*With people with complex needs you often get [people saying] – ‘oh he’ll not do it. He’ll not do it. It’s not good – we’ve tried. Don’t, he’ll not go there’*

*(Community Learning Disability Nurse)*

The role of humour and peer groups emerged as being positive experiences and ones that could be considered in implementing POCT

*And I think the patients probably did it and queued up for it [finger prick] because their friends were doing it. And I think that may be comfortable. Rather than at a GP, right, we’re going to do this now – I don’t think so. It definitely works when they’re with their peers. Or carers. Or in a more relaxed situation. Because they didn’t realise what they really... It was only a finger prick, so they weren’t too bothered about that.*

*(Specialist lead)*

The location of the testing - whether at a GP surgery, home or day centre - did not appear to matter, rather it was about the way the testing procedure was conducted. In reference to a drop in/pop up clinic experience a practitioner commented:

*But there was quite a buzz to the day. And I think having it as part of something else probably diluted the medical aspect of it. People don’t realise that what they’re doing is having a medical intervention. It almost feels like an activity.*

*(Specialist Lead)*

#### **4. 4 Culture Shift**

In exploring experiences and perspectives about adoption of POCT within the field of learning disability, two significant issues emerged identifying barriers and factors that need to be considered for this client group. The first was concerned with attitudes and issues related to the importance and ability to recognise physical health needs and the second was the issue of responding to this identified health need and whether subsequent action and follow up would be taken, which could require further investigations or treatment.

Recognition issues included clinical participants reporting that it was normal for a learning disability or resulting behaviours to be seen and addressed first by clinicians, rather than investigation or screening for physical diseases or causes. Clinicians also

reported “a different crisis level” (Learning Disability Nurse) for people with learning disabilities and an attitude of “apathy” existing towards people with a learning disability where their physical health is not prioritised and prevention of avoidable issues is not sought.

*There’s still a big cultural shift that’s needed. People with the learning disability are still marginalised. They still experience much more inequality than other populations...the things that makes its slightly different is that some of those people need their service to [be] reasonably adjusted in order for them to receive it. And that’s not always understood.*

(Specialist Lead 4)

Clinical participants and commissioners also described barriers in relation to other clinician and carer attitudes and assumptions about testing not being required, or there not being an issue warranting investigation or treatment.

*We tested his hearing – the carers thought he had selective hearing: ‘He can hear when he wants to’, all the usual things we hear. We tested his hearing, which people didn’t think we would be able to do because he had Down’s syndrome and autism. But [we] found he had a profound hearing loss, so he couldn’t hear speech at all. And it shocked me to think that his hearing is so bad, and yet the carers thought he could hear perfectly.*

(Specialist Lead 2)

The value of POCT in addressing these cultural barriers to raise both awareness and access was welcomed within the focus groups and interviews. There was an acknowledgement of the need for a system-wide approach and that “there are no quick fixes” (Specialist Lead 3), but that there may be potential for trying in respect of national and local policy drivers:

*I think the strategic landscape is right as well....that’s kind of the only show and tell, it seems, at the moment for the health service. And this work – point of care testing work – just lends itself to that model. So somehow the point of care works needs to be really closely aligned to the STP [Sustainability and Transformation Programme] work.*

(Commissioner)

## 5 Discussion

This study addressed its aims to identify experiences and perspectives related to POCT and learning disability and gain information on how this could inform future development/adoption in practice. Data was from one geographical area, and with service users who had capacity to consent and caution should be applied when applying the findings to other areas.

*Implications of findings for future development and adoption*

### *Lack of awareness of POCT*

In exploring experiences and perspectives, we found a general lack of awareness and use of POCT for people with a learning disability across all stakeholder groups. This lack of awareness of the technology and testing, is not something that has been identified as a barrier to its use in other qualitative point of care studies in primary and secondary care settings (Jones et al 2013), rather the barriers in other studies (ref) have been more about practicalities of use, cost and result confidence in comparison to tradition laboratory testing. Liikanen & Lehto (2013) identified that there was a lack of studies into the training of point of care testing for nurses and its impact on competence and practice.

The implication of the finding about lack of awareness for service users and carers is its potential to provide an opportunity to provide more information for people about options and alternatives to screening and blood tests, and as a result improve access and equity about their, or their relative's health.

For the general clinical workforce this finding might initially appear a minor issue and one that training and communication could address. In the context of learning disability nursing however, a number of reports and studies specific to mental health and learning disability nursing staff have highlighted a lack of training in the area of physical health assessment and clinical skills (Wood & Thorley 2010) and these were experiences expressed within this study. Clinical skills were described by the nurses in particular as being something that have not been trained to do, or are required to do within their current roles. It is noted that the identification and management of health risks and physical health needs by learning disability nurses is now being recognised as a greater priority and reflected in a number of strategic developments and national workforce competence frameworks for learning disability staff (HEE 2015).

The recent review of the Standards for Proficiency for Pre-Registration (NMC 2018) has resulted in physical health clinical assessment skills now being part of the core requirements for future Registered Learning Disability nurses. In addressing lack of awareness, the issue of acquiring the skills and the remit within their role to undertake testing is a factor that could affect adoption should be a key element for the learning disability workforce of any planned implementation of POCT for people with a learning disability. This issue of scope of role in undertaking health check assessment activity was not initially identified as a key aim in this study and warrants further exploration.

### *Acceptance and adoption in practice*

There was a degree of consensus by all stakeholders that using POCT could be a beneficial move. For service users, potential benefits identified were around the actual experience of going for a test being more a more positive one. For clinicians this was in relation to both making it a more positive experience as well as in relation to addressing sensitivities about having blood tests and resolving difficulties in obtaining samples, and subsequent decision making.

Actual and potential positive impact on experiences of having preparation (seeing the kit beforehand) and pre-test information were identified as being key by service users, as was the role of a known carer being present in supporting the person. This need for preparation and support for testing is not evident in the wider POCT literature, though identified as an action required to improve equity of access by Pilling (2014) in her audit study of a diabetic retinopathy service for people with learning disabilities. The implications of this finding for any deployment of POCT in practice for people with a learning disability may be less of an issue within services delivered by learning disability staff in respect of how services are configured and delivered. Application within other non-learning disability specific services may be more problematic and require specific education to ensure these reasonable adjustments are in place. **A number of initiatives exist in relation to improving the experience of contact with health services**

The potential for POCT to create improved 'first experiences' of diagnostic testing is an area emerging from these findings and warrants further investigation for its possible contribution to improving engagement with health assessments and reducing anxiety associated with the process.

A number of commonalities affecting adoption identified in previous POCT studies (Peirce et al 2014, Osta et al 2017) including health economics, practicalities of storage, quality assurance were raised but did not emerge as central themes in this study.

#### *The challenges associated with enabling access – unintended consequences*

One of the initial drivers for undertaking the study was the context of health inequity of access, and known increased risk factors for individuals with a learning disability. This coupled with concerns over diagnostic overshadowing within the field of learning disabilities led to the question as to whether using POCT would be able to contribute in some way to addressing this and people's experiences. The findings support the potential value and contribution adopting POCT could make, if adjustments were made, to both the experience and the ability to undertake a test/screen successfully.

They also raised areas for caution and concern in relation to the need to be cognisant of attitudes and reluctance by some carers and clinicians to support investigations being undertaken, reflective of the previous reports and studies about equality of access. This is not a factor has been raised in other POCT adoption studies and this may well be a cultural issue specific to this field of clinical practice, again reflective of the evidence base on inequality in health for people with learning disabilities (Truesdale & Brown 2017).

It is evident that the issue of diagnostic overshadowing is a core factor that will need to be addressed in seeking to use POCT in any learning disability care pathway to improve access to testing and screening. Diagnostic overshadowing does not appear as a major consideration deciding to use POCT in other patient pathways.

#### *Making it work*

The study generated strategies for how the adoption of POCT could be maximised within learning disabilities and help address the issues of access and more timely recognition of key health risks which have been identified to impact on life expectancy and quality of life. The factors affecting adoption included some already identified in the literature but added areas which will require consideration when seeking to implement in services for people with a learning disability.

The findings raise questions and opportunities about how and where POCT could be used. Whilst the context of this study was about health checks and access to health assessments, our findings provide information that could be used to further explore the use of POCT in other settings and circumstances such as primary care.

## Recommendations

- Undertake awareness raising within the learning disability and primary care workforce on the potential use of POCT, including hearing loss assessment
- Review workforce skills competence frameworks to include POCT awareness and testing as a means to address inequity issues
- Review guidance to include strategies for success in adapting POCT for learning disabilities<sup>1</sup> including guidance on diagnostic overshadowing and testing equity

## Limitations

While the sample lacked service users with fluent language who were able to verbalise their views freely, a strength of this sample is that less verbal participants had opportunities to give their views through the use of role play and a known carer being present within the focus group. The sample was limited in its representation of the wider spectrum of learning disability including individuals with complex and profound needs.

The sample of clinicians, service providers and stakeholders all had an interest in learning disability. This is likely to have influenced the views offered in this study. The views of those that have no special interest were sought by sending information to all clinicians in the network, but only those with an interest in learning disabilities responded.

## Conclusion

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<sup>1</sup> A guide for using POCT for people with a learning disability was produced as a result of this study

This evaluation has taken the first steps to explore the feasibility and acceptability of point of care testing for people with learning disabilities. Point of care testing has the potential to enable access to a range of diagnostics for people with a learning disability, however this needs to be with some adjustments. The area is complex and has underlying ethical and clinical decision-making challenges, and further work is needed, however point of care testing appears to have a valuable role in improving health equity for people with a learning disability.

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