Making Time

Making History

Transforming Lives

Final Report

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Glossary of Terms and Abbreviations

Anharmony	The lack of fit between what they each do and what others expect can sometimes cause tensions. We've used a fancy word, 'anharmonies', to describe this lack of fit
'at hand'	Attending a training event and the recall you have later
BILD	British Institute of Learning Disabilities
BMJ	British Medical Journal
BPS	British Psychological Society
CCG	Clinical Commissioning Group
Clock Time	The time that is represented by the dials on a clock
CPPE	Centre for Postgraduate Pharmacy Education
CPWY	Community Pharmacy West Yorkshire
CVD	Cardiovascular disease
Disclosive Space	When you have built a relationship with someone to such an extent that you feel comfortable and confident to disclose things you might not have done
DoH	Department of Health
DRC	Disability Rights Commission
DWP	Department for Work and Pensions
Equipment	Communication tools you might use in daily practice to make yourself understood to include words, tone of voice, non-verbal communication etc.
LC	Locally commissioned
LD	Learning disability
Homogeneous	Relating to one concept e.g. 'person'; very specific
HCP	Healthcare Professional
Heterogeneous	Relating to multiple mixed concepts e.g. 'persons'; more general
Lived Time	The time that is spent without looking at the clock e.g. lunch with friends vs a lunch hour
MDS	Monitored Dosage System
MT	Making Time
MUR	Medicine Use Review
NCD	Non-communicable diseases
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
NMS	New Medicine Service
Person	The singular unique person
Persons	A group of singular unique people
PHE	Public Health England
Population	Grouping of people based on a single characteristic, e.g. LD without taking into account their human nature; reductionist term
PSNC	Pharmaceutical Services Negotiating Committee
PLWLD	People living with a learning disability
RCGP	Royal College of General Practitioners

RCT	Randomised Controlled Trial
‘ready-to-hand’	Things that you might use every day to support you such as Easy Read materials
RPS	Royal Pharmaceutical Society
WHO	World Health Organisation

Executive Summary

1. In Making Time, Making History and Transforming Lives, there was a need to think afresh about the approach used with persons experiencing chronic conditions. This study has created a model, a language and a methodology for exploring and developing further such a model.
2. In an attempt to humanise the patient, they were described as a person and to further commit to understanding the person, they have been described not as a patient *'with'* a condition but a person *'living with'* their condition as it was felt this better captured the sentiment of the qualitative nature of the research.
3. The purpose of this project was to focus on offering a structured approach to a group of difficult to reach patients living with a learning disability (PLWLD). These patients were known to suffer increased morbidity and a reduced life expectancy and so Making Time was developed.
4. Only around 20-25% of PLWLD were known to GP services especially those living with borderline/mild LD. This requires further research as these patients experience high rates of physical ill health and have a reduced life expectancy.
5. In Making Time everyone involved in the project was concerned to find ways of opening new social space for each PLWLD, in order that they each become empowered in their own world of practice in continually moving towards re-freshing, re-energising, re-vitalising aspects of their own lives.
6. Pharmacists are the third largest healthcare profession (HCP), having undertaken 5-years of Master's level education and training, accessible to all members of the public without appointments; the scientist on the high street. They are an underutilised phenomenal asset and the general population need a greater understanding of what community pharmacists can do.
7. This evaluation explored if the Making Time service achieved its intended objectives; Was it effective? Was the application of the Making Time service feasible in the realms of community pharmacy? What was found was that when PLWLD engaged in the service, it was very successful in achieving excellent health-related outcomes.
8. Methodologically, due to the small number of stakeholders, PLWLD and community pharmacists, a qualitative case-based ethnographic approach was

followed to illuminate the experiences of the PLWLD in working with community pharmacists.

9. Qualitative research was used to explore and develop theories and ideas based on this small number of participants where meaningful statistics would be impossible. This could then lead to wider trials of an intervention, based on the outputs of this research.
10. The project centred upon the work of 20 community pharmacists and 200 'persons', located on the South and West side of Leeds. In attending to their styles of practice, and in uncovering the value of 'Making Time' in helping patients in Making History for themselves, this project has also begun to make its own history. Its value therefore was in generating a new model for care of persons living with chronic health-related situations; each with their own unique express languages.
11. The Making Time project was developed by NHS Leeds North CCG and Community Pharmacy West Yorkshire in partnership with Leeds City Council Adult Social Care Learning Disability Services, Leeds and York Partnership NHS Foundation Trust and, most importantly, service users.
12. Making Time would not have come into existence without the dedicated work of the stakeholders including a GP, community pharmacists, executives, PLWLD, commissioner and a manager. All had the passion to realise that Making Time could make a difference to these patients.
13. The service's mission statement was *'to try and make sure people with learning disabilities get the best service they can from their community pharmacy. It's about making sure that pharmacy services can offer the kind of person centred service that people with a learning disability really need to stay safe and well.'*
14. Methods of data collection included semi-structured interviews and participant observation in their authentic setting thus giving an ethnographical aspect to the research.
15. Method of data analysis involved transcription of the interviews with community pharmacists, stakeholders and PLWLD with the use of both an analytical framework and constant comparison illumination.
16. Engaged community pharmacists thought Making Time was a great success for them as they felt that they had been empowered to support PLWLD thus

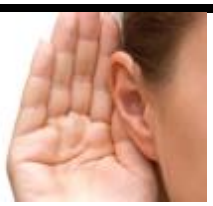
increasing their confidence in discussing a patient's health and well-being in the setting of a community pharmacy.

17. Community pharmacists who had not managed to engage in the project, as expected, reported that they had the challenge of the unknown and unexplored difficulties in effectively communicating with PLWLD.
18. Stakeholder reflections opened space for further reflection upon the need for additional training for community pharmacists in order to enhance their clinical and communication skills in working with PLWLD.
19. Patients thought easy read resources were an obvious success that open the space to think about the language practices of PLWD.
20. There was a need to reflect and consider that *'at hand'* (e.g. training events) resources were different to *'ready to hand'* (easy to read materials) resources and that simulation, ongoing coaching and support are vital to any new initiative.
21. Making Time clearly demonstrated that new communities can begin with one person and they can always grow further.
22. For any person, being ready for anything new or innovative is person specific not persons specific; this was exemplified by the amazing success of small numbers of community pharmacists and PLWLD. What they did to foster their successes is worthy of further research.
23. There was a discovered theme from this research about an emergence of diverse educational/pedagogical contexts for development of new public health initiatives.
24. The gift of time and space was pivotal in also creating the necessary professional time and space for them to work with PLWLD, in their clinical capacity as caring community pharmacists.
25. All community pharmacists agreed that they felt they had the skills to offer such services and a proposed expansion of Making Time could be to consider a similar 'year of care' model for other patients with chronic health conditions.
26. Easy read resources were extremely helpful in training new pharmacy staff on an introduction to medicines, in particular psychotropic medicines.
27. A major success of the project revealed in this evaluation was in opening space for a small number of PLWLD to encouraged them to make significant and sustained transformations in their lifestyles; radical transformations in their everyday worlds of practice.

28. Making Time gave community pharmacists an opportunity to engage in caring conversations with PLWLD earlier and use the *'ready to hand'* resources to set patient-led goals and reinforce through the longevity of service provisions.
29. There was a very powerful dimension in that community pharmacists were able to engage in detailed, sustained person-centred educational conversations around public health goal setting with PLWLD.
30. PLWLD had limited capacity to use the English language and used a variety of non-verbal communication including informal signs and body language in a very innovative nuanced manner.
31. PLWLD were empowered to make their own histories as they worked towards transforming aspects of their lives; pivotal to this was the Making Time project team, community pharmacists and their teams.
32. The traditional training model used in this project was successful in achieving what it set out to do and it also introduced community pharmacists to the challenges of working with PLWLD.
33. To enhance training provision, ongoing coaching through critical dialog and setting up of 'communities of practice' for community pharmacists would be valuable to consider in future projects.
34. Participant community pharmacists were seen to be reflecting during conversations about all aspects of their practice and development as a leading-edge HCP. Clinical practice involving listening to PLWLD required reflective practice to understand and be conscious of this different type of communication with patients.
35. During this evaluation and listening to each person, the conversations were deconstructed and unpicked to challenge the objective/subjective models of healthcare. These were re-labelled so the concept of time became 'clock time' and 'lived time' to clearly describe the difference between 10 minutes on a clock and a conversation without clock time boundaries.
36. The project required the evaluators to develop a new methodology to illuminate the unique situated nature of each person's world of practice. By developing cases around this developed methodology, it sought to uncover how PLWLD were being transformed by their interactions with their community pharmacists.

37. The time and space created through Making Time in their local community pharmacy gave PLWLD a safe place to build confidence, socialise and feel comfortable with the pharmacy teams.
38. The more work done in community pharmacy normalising conversations about public health with the local population, the more community pharmacists will be recognised as hubs for health and well-being.
39. When working with people, everyone is unique and different so that care cannot be standardised as it will 'fit' very few people. Instead, there needs to be fluidity around service provision that can account for working holistically with patients who are living with a chronic condition such as an LD.
40. The model for Making Time could be adopted for any patient *'living with'* a chronic condition to offer a *'year of care'* model to support patient outcomes; a type of Medicines Use Review plus (MUR+).
41. This terminology opening space for '*listening to'* the person in their '*everyday practices'* creates a ground for a provisional theory of how knowledge is developed of practice in working with persons with chronic conditions.
42. Transferable skills were developed by community pharmacists that could be used with other patient groups for a holistic approach to public health and patient goal setting.
43. HCPs need to understand that PLWLD have a multiplicity of sophisticated and nuanced communication practices that they were not necessarily aware of and may find difficult to understand at a first meeting. With sustained engagement, such as the Making Time project, this mutual understanding grew and developed.
44. A model was developed that is being explored that could be used to develop a toolkit to help community pharmacists and other HCP in understanding how to improve the support given to persons with chronic conditions affecting their health and well-being.
45. This evaluation also opened further reflection upon developing the clinical and communication practice of community pharmacists in the community; how and upon what basis their practices might be transformed.

Lay Summary

200 people registered for the project	
People went to their pharmacy and saw them every month	
We listened to them	
They were happy	
One woman stopped smoking	
One man went swimming everyday	

Many visited their pharmacy	
It made us think about people with a Learning Disability	
We had lots of ideas to help	
We need to do more work to help more people	

Introduction

'Making Time' was a pilot project designed to learn more about how to improve the care experienced by people living with a learning disability (PLWLD) in community pharmacy practice. Of course, this opening sentence raises more questions than it answers. These include understandings of human beings, of experience, of disability, of community, of pharmacy, of practice, and the issues they raise; not least so that more might be learnt from this project.

When Robbie Turner, former Chief Executive Officer at Community Pharmacy West Yorkshire (CPWY) along with his team had viewed the issue of 'Making Time' in terms of a 'gap' in provision, it was approached with the aim of learning as much as possible about how to improve care for people with a whole range of Learning Disabilities (LD). The objective, in so doing, was to learn more about how to improve community pharmacists' care of all their patients. On reflection, in conversation with Turner (2018), he also reflected from his own experience, on the need to make *'time'* and *'space'* for PLWLD. He was not speaking just of clock-time, or measurable spaces but also of lived time and spaces that could be developed in a community pharmacy for PLWLD.

For example, when we meet a friend we give them a hug. In that social space, we make with the other, don't we often seem to lose track of time when we're talking or listening or getting something done purposefully with someone else? In contrast, when we meet somebody professionally, we don't usually give them a hug, but we might shake hands. Don't we emerge from this interaction with a different sense of the social space we make in this professional setting? Similarly, our sense of how long something takes might be different. In hugging a friend we're often not aware of how much time has passed, whereas when we meet a new colleague, we may be acutely aware of the passage of time. Indeed, Turner also had in mind the ever incalculable *'lived time'* and *'social space'* that we all variously, and largely unconsciously, make and re-make each day, in and through the factors at play in what we do in our social and professional interactions with others.

At issue in working with all human beings in community pharmacy, therefore, there was both a homogenous dimension of our everyday practices in which what was considered possible professionally is calculable and conditional upon a range of precepts relating to each particular case. Additionally, there was what might be called a heterogeneous dimension to our practices; recognising unconditionally the impossible to measure or define, incalculable dimensions of such everyday practices. As individuals, we have variously cultivated a number of ways of handling such impossibilities. In meeting someone for the first time, do we not variously draw upon our own moral and aesthetic criteria in making sense of them; we *'pre-judge'*? In the education and training of community pharmacists and of other HCP, such subjectivity tends to be avoided and labelled as *'softer skills'*. But, from a psychoanalytical perspective, since Freud's work there has been recognition and much debate about the possible 'pay offs' from such subjectivity; peoples' experience of happiness and joy.

Background to Making Time

Making Time project was launched in 2015 by the NHS Leeds North CCG and Community Pharmacy West Yorkshire in partnership with Leeds City Council Adult Social Care Learning Disability Services, Leeds and York Partnership NHS Foundation Trust and service users. It was aimed *'to try and make sure that PLWLD*[1] *got the best service they could from their local community pharmacy. It was about making sure that pharmacy services could offer the kind of person centred service that PLWLD really needed to stay safe and well.'*[2] Inspiration for the project grew from listening to the concerns of people who were using the Leeds Disability Care Services. It was co-developed by Nigel Hughes, Head of Public Health Engagement for CPWY in collaboration with LD Care services, the NHS and Leeds City Council.

Making Time was about building upon the services that PLWLD already received and to enhance these by being more pro-active using a year of care approach in order that they received accessible person-centred support for using their community pharmacy services; supporting their well-being and a healthy lifestyle. This service allowed PLWLD to look at their health and lifestyle-related goals with their community pharmacist to make them realistic and achievable. The objective of this evaluation was first to celebrate the successes of this project and in so doing, to look back at it through the lens of critical reflection in order to learn more about how it might be developed further. It was important that feedback from the project was evaluated in order to determine to what extent patients and/or community pharmacists felt that patient needs or goals were being met as intended.

Background to LD

Department of Health (DH) define LD as a *'significant reduced ability to understand new or complex information, to learn new skills (impaired*

[1] The distinction made here is that the person is 'living with' as opposed to a 'a person with' as this can often lead to a reduction of the person to the condition with the focus shift from person to condition subconsciously.
[2] Adapted from the Making Time mission statement

intelligence), with a reduced ability to cope independently (impaired social functioning), which starts before adulthood' (DoH, 2001)[3].

In their definition they use the word *'impaired'* such that something is missing from the person. A decade earlier, Hammill (2001)[4], aimed to review a number of conceptions of LD, *'few topics in the field of LD have evoked as much interest or controversy as have those relating to the definition of the condition'* (ibid: 74). He noted how, from *'Samuel Kirk's (1962) first effort to define the term… professionals, parents and government agencies have tried to develop a valid and widely acceptable definition'* (ibid: 74).

Hammill's study showed that the consensus in the USA centred upon the National Joint Committee on LD (NJCLD),

> *'LD is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and the use of listening, speaking, reading, writing, reasoning or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the lifespan. Problems in the self-regulatory-behaviours, social perception and social interaction may exist with LD but do not by themselves constitute a learning disability. Although LD may occur concomitantly with other handicapping conditions (for example, sensory impairment, mental retardation, serious emotional disturbance) or with extrinsic influences (such as cultural differences, insufficient or inappropriate instruction) they are not the result of those conditions or influences'* (NJCLD, 1981,1988:1)[5].

This definition considered a group of disorders and their relationship with the individual person. In England, there were signs that the subject-object

[3] Throughout this report the term 'learning disability' will be used, although 'intellectual disability' is the term now preferred (BILD, 2017).

[4] http://www.pearsonclinical.com/authors/hammill-donald.html

[5] NJCLD 1981 LD: Issues on Definition. Unpublished Manuscript/ (Available from The Orton Dyslexia Society, 724 York Road, Baltimore, MD 21204; Reprinted in The Journal of LD, 20: 107-08); NJCLD 1988 Letter to NJCLD Member Organisations, cited by Donald D Hammill 2001 On Defining LD: An emerging consensus, *Journal of LD*, 23 (2): 74-84

dualism was being challenged. Centre for Pharmacy Post Graduate Education, (CPPE) (2017) cite Mencap's conception of LD:
'…as a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life'[6].

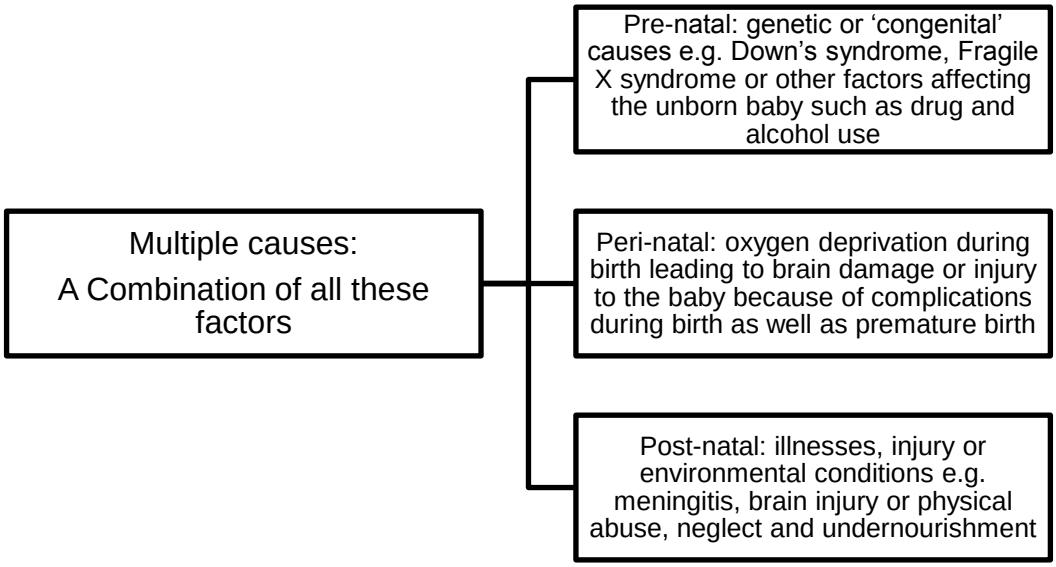
Clearly, as in the USA, this would appear to place to focus upon the subject, LD, rather than the experience or subjectivity of such disabilities. Moreover, it would appear, that the dualism between the object, the person, and the subject, LD remains, as does the merging in their definition of LD of the undergoing and suffering experienced by people. The same dualism in England was also apparent from the DH's (2001) statement on *'Valuing People'* which purported to express *'A New Strategy for LD for the Twenty First Century'*. Interestingly, DH further elaborated on their statement making references to *'experience'*, but in so doing, reduces experience to another defined subject associated with LD. For example,

- *'people with LD have greater health needs than the rest of the population. They are more likely to 'experience' mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities*' (ibid: 6, 59)
- *They can experience avoidable illness and die prematurely'* (ibid: 19).

LDs have various causes and these are categorised below however, for many, the cause is unknown.

[6] https://www.mencap.org.uk/learning-disability-explained/what-learning-disability

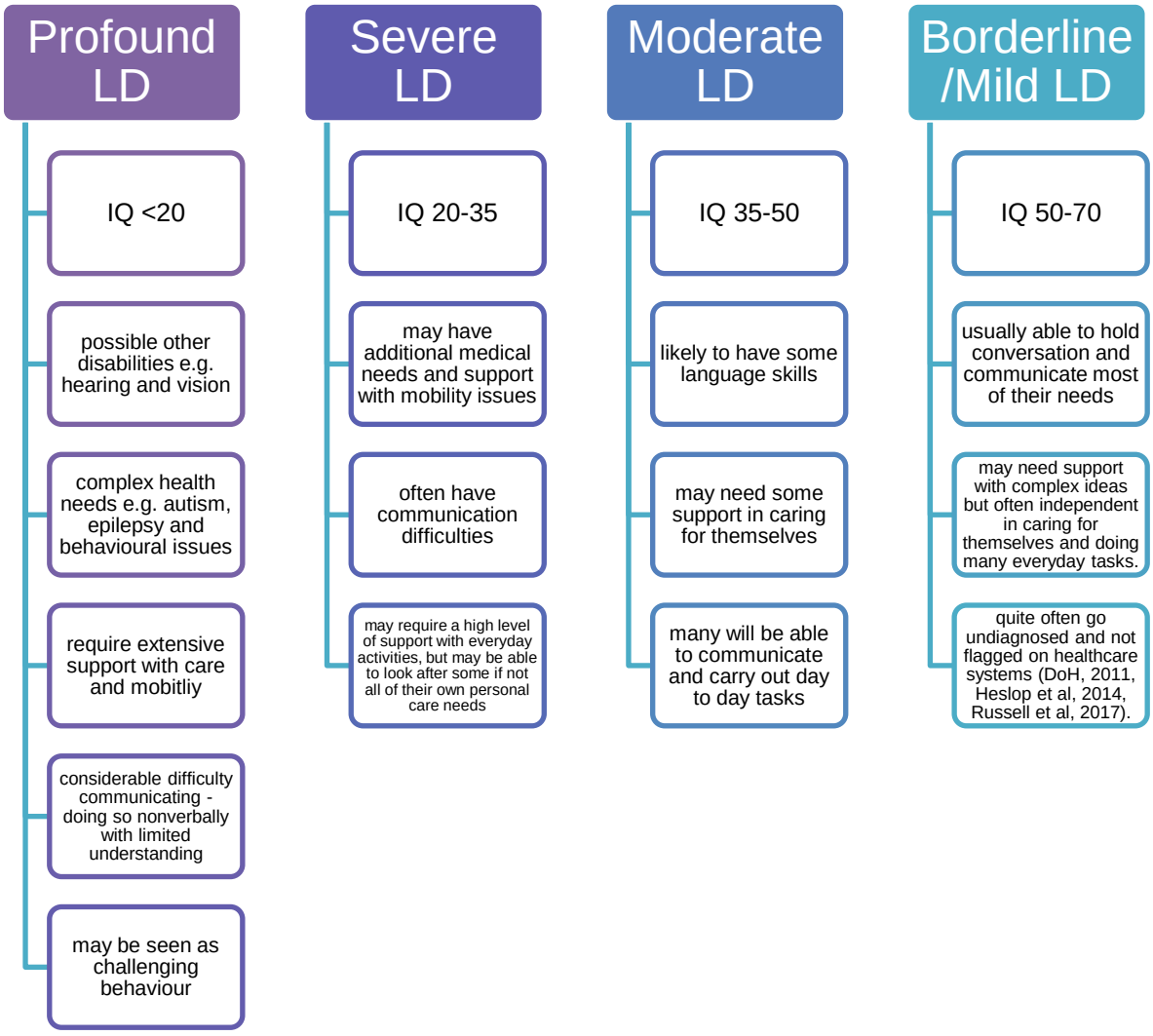
Figure 1:Causes of LDs (adapted from BILD, 2017)



These covered a broad range of individuals, each with different capabilities and requirements and there were no clear dividing lines between the groups (BILD, 2017). The terms borderline, mild, moderate, severe and profound were used to describe PLWLD by the British Institute of Learning Disabilities (BILD), (BILD, 2017, Russell *et al.*, 2017), however, there was no clear cut off point between people with borderline/mild LDs and the general population (BILD, 2017).

British Psychological Society (BPS) recommends that a diagnosis of LD required the demonstration of three essential criteria: significant impairment of intellectual functioning (IQ < 70); significant impairment of adaptive behaviour; and onset before adulthood (BPS, 2015 and DoH, 2011).

Figure 2: Classification of people with LD's (adapted from BILD, 2017 and BPS, 2015)



PLWLD in the UK tend to take longer to learn and may need additional support to understand complicated information (Mencap, 2017). The level of support needed to be tailored and according to the Equality Act 2010, public sector organisations such as pharmacies must make changes to ensure that their services are accessible to disabled people as well as everybody else. PLWLDs may require clear, simple and possibly repeated explanations of health and medication advice as well as help with managing issues of consent (Mental Capacity Act (PHE 2017)).

Health issues faced by PLWLD; what is missing?

In the UK, it was estimated that 1.5 million people have a LD which was almost 2% of the population (Mencap, 2017, Russell *et al.*, 2017), however it was thought that only a quarter of these individuals were on the LD register at their local GP surgery (Russell *et al.,* 2017). In summary, in their report Hatton, Glover and Emerson (2016)[7] presented the latest data available (taken from 2014- 2015) at the time of writing, as follows:

- *Numbers with LD*: estimated to be 1,087,100 (including 930,400 living in England) of whom 252,446 people were officially identified on LD registers. This meant only 1 in 4 PLWLD were registered and known. Hatton *et al.*, (2016) noted that there had been a continued growth of around 4% per year.
- *Number of people with LD on GP registers as a proportion of GP practice lists*: The figure for Yorkshire and Humber in which this project was located: 4.98 per 1000 GP practice population, compared with Cumbria & North East (5.59 per 1000) and London (3.36 per 1000).
- *Mortality*: Making up 2% of the population, they were at risk from the determinants of health inequalities, and if they had borderline/mild LD they may not have adequate support as the majority lived on their own.
    - They died much younger than the general population[8] (13-20 years younger for men with LD and 20-26 years younger for women with LD)[9].
    - They were at increased risk, compared to the general population of a variety of health problems[10]

In 2016, the NHS project, *Health and Care of People with LD* 2014-15, developed in collaboration with PHE, found that:

[7] Hatton, C., Glover, G. and Emerson, E. (2016) LD Observatory: People with LD in England 2015: Main Report, London: Public Health England, PHE, November.
[8] PHE (2017) Pharmacy and people with LD: making reasonable adjustments to services, London: PHE: 13
[9] DRC (2006) Equal *Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with LD and/or mental health problems* London: DRC; http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf; accessed 30 July 2017
[10] Common health problems include: obesity, diabetes, epilepsy, sensory impairments, sleep disorders, mental ill health, thyroid problems, dysphagia, asthma, gastro-intestinal problems, poor oral health, dementia, chronic pain, and heart failure (PHE: 13); Emerson E, Baines S, Allerton L, Welch V. *Health inequalities and people with LD in the UK*: 2012. PHE; 2012. Available from: http://webarchive.nationalarchives.gov.uk/20160704150527/http://www.improvinghealthandlives.org.uk/gsf.php5?f=16453&fv=17942 (accessed on 4 July 2017).

- Obesity was twice as common in people aged 18-35 with LD;
- 1 in 2 eligible females with LD received breast cancer screening compared with over 2 in 3 females without LD who received such screening[11]

Moreover, a report from the Disability Rights Commission (DRC) suggested that the levels of ill-health for this group were significantly higher than the figures imply[12]. Both the localised demographics and variations in the place where persons live, created considerable challenges at the local level in providing the appropriate forms of support as this evaluation made obvious in Leeds.

Clearly, the morbidity and mortality rates for PLWLD remain completely unacceptable. Additionally, the numbers of persons with borderline/mild LD who are not receiving adequate support remains intolerable.

In 2014 '*A Confidential Inquiry into Premature Deaths of People with LD'* by Heslop *et al.*, reviewed the deaths of 247 PLWLDs over a two year period, as well as 58 comparator cases of adults without LD. Findings were that 28% (n=69) of PLWLD died from avoidable causes[13] compared to 9% (n=5) in a comparison population of people without a LD. Nearly a quarter (22% n=54) died under 50 years, median age at death was 64 years. For males and females, median age at death was 65 and 63 respectively with the general population being 78 and 83 (Heslop *et al.*, 2014).

It was estimated that the prevalence of mental health problems amongst adults with a LD was approximately 40% (n= 560,000 adults) (Mencap, 2017), which was more than double that of the general population (Emerson *et al.*, 2011, Heslop *et al.*, 2014). This with co-morbidities such as autism, anxiety and epilepsy (Sheehan *et al.*, 2015) meant PLWLD had a higher chance of being prescribed one or more psychotropic medications (Johnny and Mahan, 2010). National Institute for Health and Care Excellence (NICE) guidelines

[11] NHS Digital (2016) Health and Care of People with LD , London: NHS, http://www.content.digital.nhs.uk/catalogue/PUB22607/Health-care-learning-disabilities-2014-15-summary.pdf; accessed 30 July 2017.
[12] DRC (2006: 6) http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf; accessed 4 August, 2017
[13] 'avoidable' according to Mencap is those that could have been avoided by the provision of good quality healthcare

(NICE, 2015) recommended the use of antipsychotics for *'challenging behaviour in people with intellectual disability and only under specialist supervision and for short periods'*. Their quality standard stated that written information should be available in an appropriate language or format, staff should clearly explain any clinical language and check that the person understands what is being said (NICE, 2015).

Research showed that 20-40% of PLWLD were prescribed anti-psychotics (Johnny and Mahan 2011, Sheehan *et al.*, 2015) which was double that of the general population (Sheehan *et al.*, 2015). In many instance, anti-psychotics, which were the most commonly prescribed medications for PLWLD, were prescribed for their sedative effects rather than for specific antipsychotic effects (Johnny and Mahan, 2010, Sheehan *et al.*, 2015, DoH, 2011). A study in primary care by Sheehan *et al.*, 2015 found around 70% of anti-psychotics were given to PLWLD in the absence of a record of several mental illnesses. This finding was comparable to other studies that found most anti-psychotics prescribed to PLWLD were given to manage behavioural problems rather than mental illness (DeKuijper *et al.*, 2010, Sheehan *et al.*, 2015, Johnny and Mahan, 2011).

What was in danger of being lost in this review was that the reduction of PLWLD experience to a definable subject, where the many nuances, complications, and unpredictable dimensions of peoples' stories of *'living with'* LD that arise from their undergoing day-to-day interactions with others. Nevertheless, Mencap did provide numerous concrete examples on their website of people's experiences given expression in many stories of *'living with'* some may view as their disabilities in learning. Why, then, does any notion of experience signally fail to enter officially legitimated conceptions of learning disability?

Cassell's (2004, 2014) research for many years was focussed upon people's experience of medicine and of the person. He suggested that the challenge for the doctor, and here we might include the community pharmacist, was *'to know the person'* as much as about, in this case LD (Cassell, 2004). For him

'the job of the twenty first century is to discover the person' (ibid). Indeed, whilst recognizing that the individual was unknowable, Cassell conceived that the doctor's task was to know as much as possible about the person. This approach certainly carried with it a challenge for so-called person-centred medicine and care.

Government Policy; What's missing?

Over the last twenty years there has certainly not been any shortage of political rhetoric shaping policy for this group; for example:

- *'No voice unheard, no right ignored'*[14];
- *'Winterbourne View: Time for Change'*[15];
- *'Transforming Care: Next steps'*[16];
- *'Patients first and foremost: The initial government response…'*[17];
- *'Learning Disabilities Mortality Review Programme'*[18];
- *'Caring for our future', Transforming care – Next steps'*[19];
- *'Fulfilling potential: Making it happen'* (Department for Work and Pensions, 2012).

Common to each of these initiatives, however, was the absence of any consideration given to listening to this body of *'persons'*; the absence of any thoughts about their worlds of practice, their unique languages (formal and informal), and the absence of any express concern about the ways in which experience always exceeds any possible subject-object grammar. In representations of practice, the person was often, quite un-problematically,

[14] DH (2015) *No voice unheard, no right ignored – a consultation for people with LD, autism and mental health conditions*, London: DH, Cm 9007; https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409816/Document.pdf; accessed 1 August, 2017

[15] Stephen Bubb (Chair of Steering Group) (2014) *Winterbourne View – Time for Change: Transforming the commissioning of services for people with LD and/or autism*; https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf; accessed 1 August, 2017

[16] ADASS, CQC, DH, HEE, LGA, NHS England (2015)*Transforming Care for People with LD – Next Steps*, https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf; accessed 1 August 2017

[17] DH (2013) *Patients First and Foremost: The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, London: DH, Cm8576; http://www.hscbereavementnetwork.hscni.net/wp-content/uploads/2014/05/Patients-first-and-foremost-Initial-Government-response-to-the-Report-of-the-Mid-Staffordshire-Foundation-Trust-Public-Enquiry-March-2013.pdf, accessed 1 August, 2017

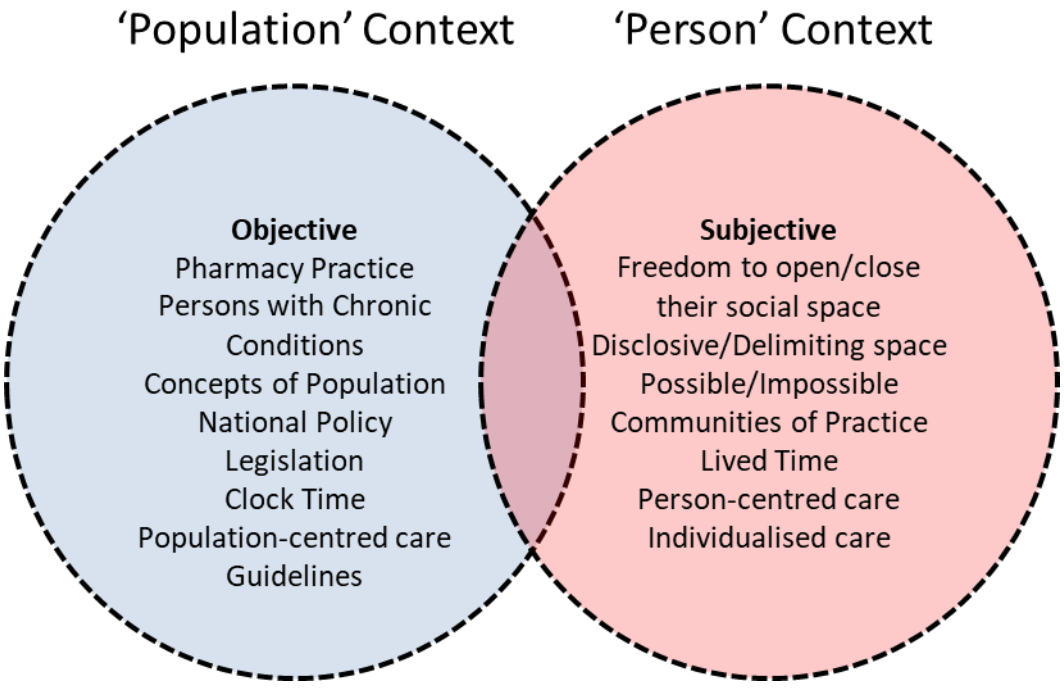
[18] Heslop P (2015) The Learning Disability Mortality Review (LeDeR) Programme, London: ADASS, https://www.adass.org.uk/the-learning-disability-mortality-review-leder-programme/ ; accessed 1 August 2017.

[19]DH (2012) *Caring for our future: Consultation on reforming what and how people pay for their care and support*, London: DH, September,https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/239393/CONSULTATION_CaringForOurFuture_acc.pdf

pluralised as *'people'*. Indeed, the assignation, 'people', provides an indication that the idiom used was referring to representation(s) and not to persons, themselves. There was rarely any consideration given to this figure of the person as both a singular figure and as a collective body. The express styles of practice of members of this group, too, simply did not feature in any of these policy documents.

It was important to summarise the concept of person and persons as described to generate an understanding of the generalisations that may be made by considering a population rather than an individual.

Figure 3: Comparison Population vs of Individual 'Person' Context or Culture



Laws of Rights: What's missing?

Human rights in law were the flip side to philosophers' questions about the person or *'being'* that person. The issue of human rights in law was complex and EU law and English law differed considerably in terms of style. In UK law,

at least four recent acts were pivotal to the governance of practice involving PLWLD:

- Mental Capacity Act (MCA, 2005)
- Health and Social Care Act (2008)
- Equality Act (2010)
- Health and Social Care Act (2012)

Once again, in seeking to address the question, what's missing, it became obvious that in current laws there was no account taken of the unique languages and worlds of each person, nor was there any consideration given to the unique communities in which each person was located. Not surprisingly, perhaps, the same was true for the approach taken in current community pharmacy practices that follow.

Nonetheless, the 'Winterbourne View[20] scandal' (2014), *'exposed by the Panorama programme'*, had been reported to have *'shocked the nation'*. It created grounds for *'a new national framework, delivered locally, to achieve the growth of community provision needed to move people out of inappropriate institutional care'*[19]. One of its recommendations at then was that measures should be taken to ensure *'there are pharmacist-led medicines reviews for both individual patients and for the service as a whole'*[21].

More recently, in the view of PHE (2017) *'Pharmacy in community settings has changed considerably in the 21st century'*. Indeed, in substantiating their claim, PHE (2016b) cite their earlier study, *'Building Capacity: Realising the potential of community pharmacy,*[22] which speaks of *'the development of proactive outreach from many pharmacies through schools, workplaces and community centres'.* As examples of such developments, PHE include *'promoting healthy lifestyles, providing a range of public* health services, such as smoking cessation support, flu vaccination, and NHS health checks'. It was, in addressing these aspects of healthy lifestyles, that community

[20] Stephen Bubb (Chair of Steering Group) (2014) *Winterbourne View – Time for Change: Transforming the commissioning of services for people with LD and/or autism*
[21] https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf
[22] Public Health England, Royal Society for Public Health. Building Capacity: realising the potential of community pharmacy assets for improving the public's health. London: Royal Society for Public Health; 2016; cited by PHE (2017: 12)

pharmacists in the Making Time project sought to provide a focus in working with PLWLD.

At the local level, the policy context for CCGs, responsible for the governance and coordination of such services had been created in the White Paper, *Valuing People* (2001) and its follow-up, *Valuing People Now* (2009). LD boards were set up to oversee the delivery of this policy and membership included NHS commissioners.

Valuing People Now (2009) included the Government's response to the independent inquiry chaired by Sir Jonathan Michael. It was commissioned as an independent inquiry by the then Secretary of State for Health, following Mencap's report, *Death by Indifference* detailing the cases of six people with LD who died while in the care of the NHS. Consonant with ILO findings, evidence from the inquiry revealed that *'people with LD receive less effective care than they are entitled to receive'*…*Ten recommendations were made to address these inequalities'*. Sir Jonathan Michael's Inquiry followed several previous reports in setting out shortcomings in access to, and quality of, both specialist and mainstream health services for people with LD'[23].

At a local level, for community pharmacists there remained the question of their collaboration with GPs, *'whose practices play a key role in coordinating healthcare for adults with LD'* (Royal College of General Practitioners (RCGP), 2012)**[24]**. Indeed, CCGs provided a much-needed framework for cultivating what might be regarded as the creativities and synergies, made evident in this Making Time report, that were required at the local level. Certainly, consonant with the visions expressed in the Health and Social Care Act (2012) and the MCA (2012), the RCGP paper, *Improving the Health and Wellbeing of People with LD*[25] placed CCGs at the very centre of efforts to transform services for persons within this group. Moreover, *'in January 2015*

[23] IHLLDO, RCGP and RCPSYCH (2012), PHE (2017)
[24] The Royal College of General Practitioners (RCGP),The Royal College of Psychiatrists (RCPSYCH, 2012: 17) *Improving the Health and Wellbeing of People with LD: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups* (CCGs), file:///Users/kevinflint/Downloads/RCGP%20LD%20Commissioning%20Guide%20v1%200%202012%2009%2024%20FINAL%20pdf%20(4).pdf, accessed 20 June 2017
[25] RCGP, RCPSYCH (2012)

the NHS invited organisations to become 'vanguards' for the new care models programme' as *'one of the first steps towards delivering the NHS Five Year Forward View'* (2014)[26] supporting improvement and integration of services'[27]. At the local level, what's missing remains consideration of the constellations and connections needed to make things happen, which, as seen in this Making Time project, extends beyond the current work of the CCGs. At the local level, therefore, much remained to be done in cultivating *'constellations'* of practices, and the necessary meaningful connections between local, regional and national level organisations and agencies concerned with improving the care of persons with chronic conditions affecting their health.

Public Health and Healthcare in the UK

In 2016, PHE produced a report called *'Fit for the Future – Public Health People'* which acknowledged that in the UK new public health challenges in the form of non-communicable diseases (NCD) were faced such as cancer, diabetes and heart disease as well as increasing health inequalities. NCDs accounted for 89% (n=557,000) of total deaths in the UK (World Health Organisation (WHO), 2016) with the four most common causes of premature mortality (adults aged 30-70) being cancer, diabetes, cardiovascular disease and chronic respiratory disease. Premature mortality risk factors for adults (aged 30-70) included smoking (22%), alcohol (11.6%), hypertension (27.7%) and obesity (26.9%) (WHO, 2014). In the UK, 15.4 million people (total population = 64m) were people living with a long-term condition and using a significant proportion of healthcare services (NHS Digital, 2016).

Community pharmacies in the UK had the potential to help meet both the short-term and long-term challenges faced by the NHS and changing population (Murray, 2016). There were currently over 13,000 pharmacies in the UK visited by over 1.6 million people on a daily basis (RPS, 2016, PSNC, 2017). As the third largest health profession, community pharmacists were easily accessible to offer services that were within the wider aims of the NHS

[26] https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
[27] NHS (2016) New Care Models: Vanguards – developing a blueprint for the future of the NHS and care services', September; https://www.england.nhs.uk/wp-content/uploads/2015/11/new_care_models.pdf

such as dealing with minor ailments and managing long-term conditions. It was widely recognised that community pharmacists and their teams were an untapped health resource (Wright, 2016, Anderson *et al.*, 2009, Mackridge *et al.*, 2017).

Community pharmacists in England have been conducted MURs since 2005 (PSNC, 2017, Wright, 2016), thereby improving patient outcomes and reducing medicines wastage (PSNC, 2017, Wright, 2016). In April 2015 the government re-focussed the requirements for the provision of MURs stating that at least 70% were to be targeted to patients prescribed high risk medicine(s) (NSAIDS, anticoagulants and diuretics), discharged from hospital; those with respiratory conditions such as asthma and Chronic Obstructive Pulmonary Disease (COPD) and patients at risk of or diagnosed with cardiovascular disease and regularly being prescribed at least four medicines (PSNC, 2017). A small study by (Latif *et al.*, 2013) found most patients responded positively to MURs with increased knowledge about their medication. The study also highlighted the lack of collaboration between GPs and community pharmacists to improve effective prescribing and optimise patient's use of medicines and thereby healthcare outcomes. MURs were positively recognised as providing an opportunity to transform the community pharmacists' role from dispensing to direct patient care.

A project that supported PLWLDs, albeit inadvertently, was *'My Medical Passport'* (MMP), a passport-sized booklet for patients to record details about their medication (Barber *et al.*, 2014). Launched in 2013, it was offered to patients through healthcare services such as pharmacies and GPs and initially designed to improve prescribing for the elderly in London but spread to other patient groups and ages. Of the 133 patients interviewed, more than half of the respondents had found their MMP useful. Almost half (42% n= 56) had used it as a platform for conversations with HCPs and a third carried their MMP around (Barber *et al.*, 2014). Mencap reported that MMP had given its service users more independence and confidence in managing their own medicines and to be able to attend GP and hospital appointments alone (Barber *et al.*, 2014). Overall evidence suggested that community pharmacist

interventions could lead to positive health outcomes for PLWLD as it would for other patient groups with long-term health conditions.

Polling by Healthwatch England in 2016 (11,000 conversations) revealed the following:

- Three quarters of people say they would go to a community pharmacist, rather than a GP to get medication for a minor illness.
- Over 50% (n=5500) would go to a community pharmacist to seek advice for a specific minor illness or injury.
- A third of people would consider using a pharmacy instead of visiting a GP for general medical advice.

Making Time in Worlds of Practice

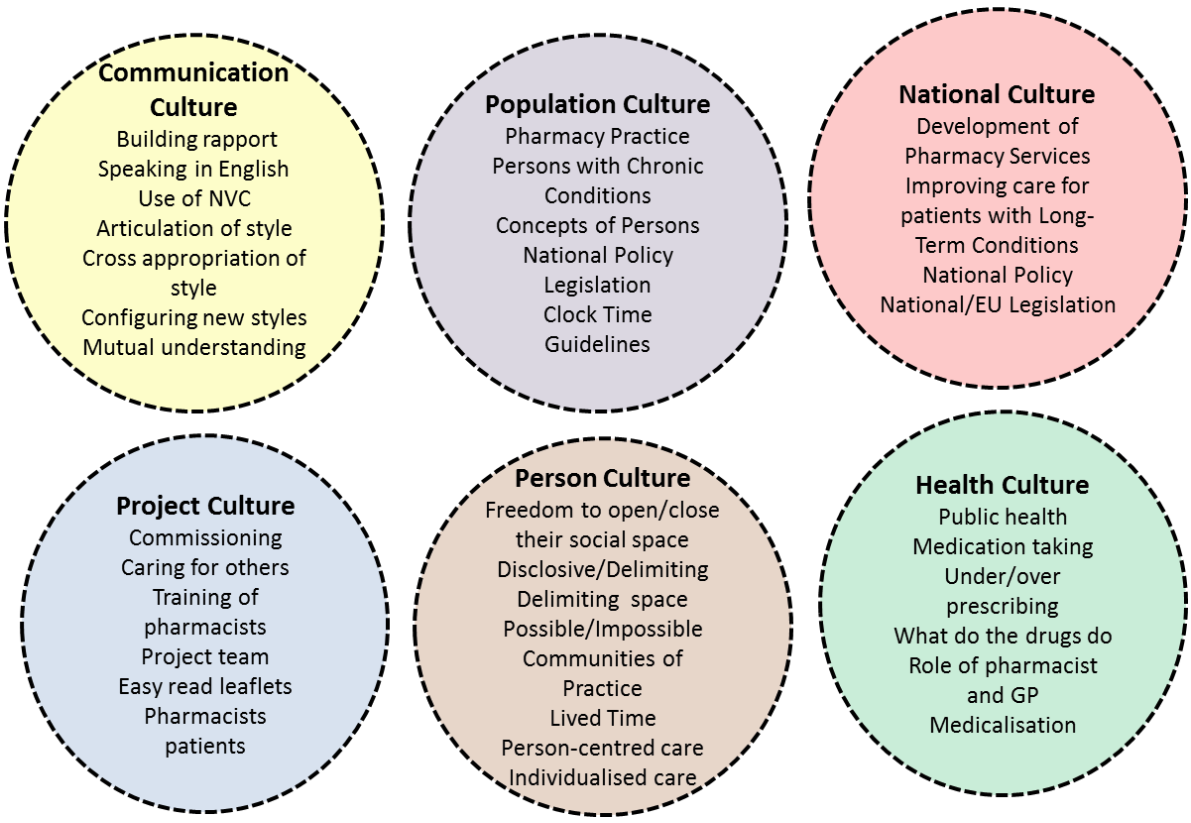
For a patient who does not have an LD, the common language is English and community pharmacists are taught to empathise and work with the patient, at their level of understanding to optimise their healthcare, medication and well-being. This was previously possible because the common thread for the patient-pharmacist interaction was the English language and an expectation of understanding from both parties; this created the possibility of a meaningful dialogue, understood by both parties. For PLWLD, the common thread as their method of communication was more complex and nuanced than the standard patient previously described so this has been described as the im-possible[28].

On reflection of what has been reviewed and uncovered so far, it seemed that most remain entirely consonant with a medical model for health. The dominant assumption in the literature on health was that somehow scientific measurement aligned with appropriate medication, and other guided measurable physical and dietary regimes, provided the basis for measured evaluations of the health of a person.

[28] Use of this word 'im-possible' in this context was to highlight the challenges faced in communication

Consequently, in remaining with this dominant medical model, as uncovered from the literature, a wide range of vital cultures reproduced in the lives of persons were simply merged by the very same institutions of state; institutions ironically in their rhetoric that continues variously to express such concern about how to listen to and to support persons labelled with LD. As revealed, these include; not least, medicine, research, education, law and the national evaluation of the health of persons. Putting these all together revealed a complex, multifaceted range of cultures in play with each other in everyday clinical practice. The way forward adopted in this evaluation was directed towards complementing and radically extending the medical model, not displacing it.

Figure 4: Making Time in Worlds of Practice; Cultures at Play



As illustrated above, there were multiple cultures at play in the care of people and this diagram represents six identified in the process of this research.

National and Health Cultures represent places where often the door may be closed to innovation and are seen to be objective and capture what might be missing as described earlier. Innovation and transformation can be seen from the Project and Communication Cultures. At the central point are the individuals and groups of individuals associated with these cultures in their everyday lives (Person and Population Cultures). By exploring these in more detail, perhaps a model of practice can be developed to support PLWLD.

Methodological Approaches and Methods of Data Collection

Background

Making Time project sought to align itself with service provision by community pharmacists currently in operation such as MUR, health promotion and signposting to develop a locally commissioned service. Therefore, the evaluation of the project needed to resonate with its philosophy.

Inception of the Project

Methodologically, the service was designed following feedback from PLWLD, guardians, carers, HCPs and other stakeholders such as policy makers who identified a need. Making Time Project Guide was developed for the project and its subsequent delivery which encompassed everything from training the pharmacy teams to data collection through Pharmoutcomes.

Pharmacy teams were encouraged to participate in the research and each pharmacy team involved was invited to training events run by service users and CPWY. They were trained to provide tailored support for PLWLD to help them to achieve their goals and more importantly deliver person-centred care in a way that was accessible and easy to understand using the resources provided. These included easy read literature, to support PLWLD in understanding how their pharmacy team could support them, their health and their medicines. A novel aspect of Making Time was that the service was remunerated and based on a *'year of care'* approach (Making Time, 2015), rather than a one-off consultation service that was the most common format for many pharmacy services such as MURs, flu vaccinations.

At the initial assessment stage, the patient's medicines were discussed together with lifestyle, health and well-being. This was followed by a series of monthly consultations, over a year, to support and encourage PLWLD to set and achieve self-determined goals and have discussions about their medicines or issues important to them relating to their health and lifestyle.

Methodological Framework for the Evaluation

A challenge of clinical practice in pharmacy, medicine and other aligned disciplines was that of working with and involving persons with chronic health conditions. There was a natural human characteristic to want to reduce the body of single *'person'* to a group of *'persons'* or populations as described in the introduction. In fact, healthcare was fraught with developing guidelines that are for a disease e.g. NICE Guidelines which really do not focus on the individual *'person'* but considered the disease. This was a challenge as HCPs sought to metricise and generalise and quantitative research focuses on a population, not individuals so hence this research was exploratory to develop theories and ideas about this project that could be tested subsequently on a larger scale. The evaluation focussed on the *'person'* and the collective body of *'persons'* and they were each located in their various communities of practices; community pharmacies, their home, their office[29].

Feedback from participants was important to evaluate in order to determine to what extent PLWLD or community pharmacists felt that this project was successful from a number of perspectives:

- How had patient needs or goals been met?
- How were community pharmacists engaging in the service?
- What were the stakeholder's views of the project?

Given the nuances of the project, methodologically the evaluation was a mixed methods service evaluation with a broadly ethnographic philosophy. Ethnography gave a systematic way of understanding the practices, behaviours and perceptions of all participants involved in Making Time. It allowed collection and analysis of the qualitative data required for the evaluation to occur in their everyday setting; the community pharmacy or their place of residence (Miles and Huberman, 1994, Smith, 2010). The research remained descriptive, cross-sectional and retrospective and focused on the effectiveness and feasibility of the project. This was from the perspectives of

[29] Lave and Wenger (2012) discuss the concepts of Communities of Practice in their book; Situated Learning: Legitimate Peripheral Participation.

the extent to which the service achieved its intended outcomes and processes and problems encountered respectively.

Literature Review

A review of the literature was completed in a systematic way using standard procedures, Boolean operators etc. Due to the nature of the project, additional literature from social sciences and philosophy was used to inform the methods of data collection for PLWLD and to attempt to explain previously unreported findings.

Methods of Data Collection

The various options for this evaluation including self-completed questionnaires, participant observations, focus groups and reflective diaries. Whatever the method, it needed to reflect the ethnographical dimension to this work and so be close to the participant natural setting; their home or their pharmacy.

Semi-Structured Interviews

The format used for the method of data collection of this evaluation was broadly a semi-structured interview. These were seen to be most appropriate as participant views were more likely to be expressed in a *'semi-structured'* design compared to a standard interview or questionnaire (Mujis, 2010, Flick 2006). They created social space for participants to express themselves in their own terms in response to a series of open-ended prompting questions. Topic guides were developed to capture perspectives of participant community pharmacist and stakeholders (Flick, 2006). These were audio recorded, anonymised, given pseudonyms and transcribed verbatim for subsequent data analysis.

In approaching this evaluation, what remained less well explored or elaborated was the ways of *'listening to'* PLWLD. Whilst talking to stakeholders and community pharmacists, the common language was English

and the level of communication and cues between the researcher and participant was common and known. For PLWLD, the practice of listening to them was not a matter of grasping and placing what was said within the same context as the community pharmacists and stakeholders; the evaluation needed another perspective of maximising communication between the researcher and the PLWLD. To do this, the *'off the shelf'* semi-structured interviews were not sufficient and interactions with 'persons' with LD required the researcher to open space for them as 'persons'; in which their unique community-based context became able to be seen (disclosed/disclosive space) and revealed.

Therefore, in listening to *'persons'* in a clinical setting it was vital to remain mindful of the requirement to create disclosive space for the other person, together with the recognition that each *'person'* lived within the interplay of both what was possible for that *'person'* and what was *'impossible'*. It was in the space opened by the interplay of possible/impossible that persons gave expression to their own particularities, idiosyncrasies and desires and in this space *'persons'* had the freedom to live their lives as *'persons'*. Clearly, too, the outline approach involved listening to others which respected and opened space for them as unique *'persons'* involved in the interplay of the possible and impossible also had implications for the methodological approach used in this study. It also affected how the analysis of the practices of persons with LD in their interactions with community pharmacists and other support staff was undertaken.

The model of practice developed therefore had to incorporate a variety of facets. It needed to open a space in the model for understandings of each person's *'grasp'* of this background to their world of practice in each of their own unique languages. From this it could be possible to make an understanding of hints of the meaning of overt particular acts of intending, and what may have been intended. In short, in listening to other *'persons'*, and in creating a model with the space for freeing them to express things in their own unique ways, it was important to keep open what specific *'background'* that had each used and any possible *'meanings'* they each gained from their

practices. It was vital for the research to uncover their worlds, their goals, their networks and how, in practice they were linked and organised by each person. In listening to these PLWLD it was a reminder that play of the possible and impossible for them could be cultivating any webs and knowledge; enabling them, thus, as free agents at last in their very education of the research and researchers.

It was fundamental to uncover more about what things were freed within the world of each *'person'* in their own unique languages; each person's unique modes of expression, therefore, gave some indication of the disclosive space they each created in their use of signs. As the philosopher, Heidegger (1978), put it, *'our disclosure of a world frees entities'*.

Field Notes and Memos to Self

As the evaluation was taking place, all of the researchers involved, aligned with qualitative principles kept field notes and memos to self. During this time, any reflections on the interviews or ideas for the research were captured for subsequent review and inclusion.

Pharmoutcomes and Making Time Documentation

Data was collected by pharmacies throughout the project to enable the impact of the service to be evaluated alongside further research to build an evidence base for future pharmacy services. Records of each client over the course of the project were made, which gave valuable data on the types of services offered to PLWLDs. Data was recorded online by participant community pharmacists on *'Pharmoutcomes'*, a secure web-based system that pharmacies provide/record services and commissioners could audit and manage these services. Additionally, all associated paperwork from the Making Time project was reviewed.

Sample Size and Sampling

The sample was 'purposive', which was common in qualitative studies (Smith 2010). For the purposes of this evaluation, a range of stakeholders identified by CPWY, all community pharmacists and patients who had signed up for Making Time were approached to participate in the evaluation. On agreeing to participate, a mutually convenient time was arranged for the interviewer to meet with the interviewee at their place of work or residence/day centre (PLWLD). Some stakeholders had moved to another part of the UK and these were contacted and interviewed over the telephone.

Methods of Data Analysis

Data was collected largely in the form of recordings which were transcribed, field notes and memos to self were added to complete the data set. For participant community pharmacists and stakeholders, a framework approach to analysis was adopted which sought to identify trends and differences between community pharmacist views and develop themes and ideas about the data. For PLWLD in the project they brought multiple perspectives that emerged from their practices involving new languages and expressions. This meant that a novel method of data analysis needed to evolve in order to make the most of the interactions with PLWLD. This was achieved by initially analysing two formative preliminary cases which were used in refocusing the methodology and data analysis for the remaining cases. In preparing the ground for the case analysis, terminology introduced earlier was used to summarise the data into cases for further review. At this stage, standard observations of practice were deconstructed to their composing elements in order to uncover more that would remain missing from standard ethnographical approaches. Transcripts and recordings were listened to/read repeatedly looking for emergent themes and ideas across the data set. This gave uniqueness to the developed methodological approach with PLWLD as it combined ethnography and illuminative enquiry.

Ethical Consideration and Ethics

Ethical approval was granted by the Chair of the Biomedical, Natural, Physical and Health Sciences Research Ethics Panel at the University of Bradford on 17/02/17 (EC609). For this study to be successful it was vital that community pharmacists were able to speak freely without repercussions e.g. from employers and were aware of this before consenting to the research. Therefore all data was anonymised using codes and were held securely in encrypted files. There was the option to opt out at any point during the data collection.

In accordance with the ethics grounding this study, each of the participants were given a pseudonym in order to protect their identity. In practice, three of the interviews with persons also involved the person's carer, while the fourth *'person'* (labelled with LD) interviewed asked to talk with the researcher alone.

It was acknowledged in qualitative research that, due to small numbers that researcher perspective or bias needs to be considered. Participant community pharmacists were interviewed by a practicing community pharmacist, so this could have supported the research in that both parties had similar backgrounds so the disclosive space they required to optimise the interview could have developed faster and hence have seen more openness and transparency. Conversely, the opposite could have occurred and somewhere in the middle was a perspective. Stakeholders and PLWLD were interviewed by a very senior educationalist and philosopher who has a range of experience including working with under 16s as a teacher and in Higher Education Institutes. His perspective would be very different to the pharmacist researcher. This was all built through an academic pharmacist who had wide ranging expertise of particular relevance here in communication and consultation skills, developing qualitative research for pharmacy and educational evaluations.

Triangulation

To assure the quality of qualitative data, it was necessary to triangulate any findings to other elements of the study. Triangulation was a term used in navigation and surveying: people discover their location on a map by taking bearings from landmarks, so identifying their location from where these bearing lines intersect. Initially, the forms of triangulation sought to uncover more understandings of the practices of each of the three groups involved in the project (i.e., the project team, the community pharmacists and the persons). For example, the data collected from Pharmoutcomes was used to validate/triangulate other results of this study. The move towards 'thick descriptions'[30] of each person's practices, characteristic of ethnography, were based on many hours of engagement with the findings to produce a clear focus upon the practices of persons – with other theories 'bracketed' out of the way.

Four forms of data triangulation[31] were used:

- *Methodological triangulation*: by using the principles of ethnography coupled with reviewing emerging phenomenon about how the participants lived in their world and that nature of their communication.
- *Data triangulation*: Using different sets of data: in working with each of the *'persons'* the interviewer collected data concerned with their use of signs in addition to noting what each had said in the semi-structured interviews.
- *Investigator triangulation*: The interviews of the five community pharmacists in the study were conducted by one interviewer, while the interviews of the project team and the PLWLD were conducted by a different interviewer and this was led by another member of the team. The discussions and reflections upon the data following the interviews then gave the basis for generating a complex range of perspectives on the practices involved.
- *Theory triangulation*: By drawing insights from a number of theories around phenomenon, about how participants lived in their world and the

[30] Scott Reeves et al., (2008)
[31] Norman K Denzin and Yvonne s. Lincoln (2005) 'Introduction: The Discipline and Practice of Qualitative Research' in, Norman K Denzin and Yvonne s. Lincoln (eds.) *The Sage Handbook of Qualitative Researc*h (3rd Edition), London and Thousand Oakes, CA: Sage Publications: 1-32.

nature of their communication, this opened up a language for the understandings of practice involving persons who have limited, and in two cases, no use of formal English

Results and Discussion of Results

Introduction

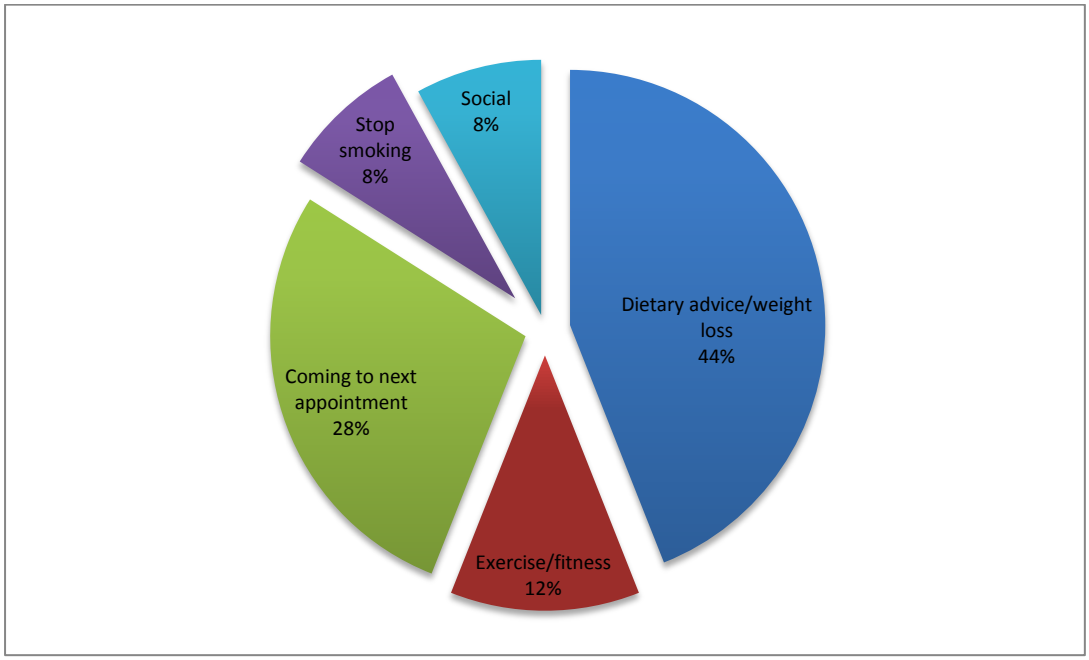
The most impact for the research team in this evaluation were the engaging and thought-provoking conversations that were had about the Making Time Project. Results in standard reports are usually listed as tables and there is conventionally a discussion of the results as a subsequent section. In order to give justice to the findings, this section presents results and discusses some of them at the same time leading to a more integrated and reflective account. By integration of findings from different participant's perspectives, a more holistic approach to reading of the findings of this analytical illuminative evaluation. The research evolved, and the researchers found that, in talking to persons, their thinking around PLWLD and community pharmacists also evolved. This section makes an attempt to re-present and analyse these conversations so, in some parts, the reflection of the researchers did inform future interactions with patients and this is represented accordingly. Using the figures in the introduction, together with ideas emerging from the research and the two formative cases, this led to some theories and ideas about how to develop a common understanding of PLWLD, their uniqueness and how this could be used to support PLWLD in future initiatives. In uncovering the relationships between patients and their community pharmacists, their words and reflections mirrored each other so this also needed to be unpicked. For example, in clinical practice some community pharmacists used laughter and simple problem-solving/heuristics techniques as equipment to engage persons as part of their strategy to create pictures in-order-to help their patients become ready for making sense of aspects of their medicines.

Making Time; PharmOutcomes Data

The project was piloted in 24 pharmacies in Leeds and almost 100 patients were registered on the service aged between 35-85. Only half of the pilot sites (N=12) managed to register patients and 31 patients had a 'Making Time' initial assessment with an average consultation time of 20 minutes. Of these; 3 were smokers, 13 were overweight or obese and 18 described themselves as moderately inactive or inactive. From the perspective of medication 87% (N=26) were taking regular

medicines of which 88% (N=23) used Monitored Dosage Systems (MDS) and 61% (N=19) had more than four regular medicines. When goal-setting, 24 patients had an average of 2 goals set and these related to the following areas:

Figure 5: Types of Goals Set for Patients



Making Time; Interactions with Persons

From being in contact with all identified community pharmacists, PLWLD and stakeholders, Table 1 shows the numbers of participants that contributed to the research.

Table 1:Contributions to the Discussion of Results

Group	Contribution	Number of contributors
Stakeholder Group	Reflections, thoughts and shared observations based upon experience gained from setting up the innovation through to the implementation of the project	6[32] (including; 1 GP who was the lead for clinical practice involving persons labelled with learning disability; 2 lead executives with experience in community pharmacy; 2 lead managers from the social services who coordinated the production of the Easy Read materials)
Community Pharmacists	Reflections and observations from their experiences of working with persons	5
Persons (each labelled with LD)	Through participant observation of the practice of responding to questions, in addition to responding to questions from the interviewer.	6; 2 of these were identified prior to interviewing and used to formulate a plan to interview the 4 persons that came forward from the project

Making Time; Implementation of the Project: Project Launch

Much thought went into the presentation given at the Project Launch. Such investment was certainly appreciated by all participants and a straightforward lecture style didactic presentation with detailed accompanying notes and connections with an interactive website was delivered. In practice, for many of the community pharmacists, the later evaluation suggested that much of the technical details presented at the launch were not transferred into practice.

In this critical reading of the training given in the project Rosemarie, Joseph and others in the stakeholder group made the evaluators aware that much consideration had gone into the initial workshop provided for community pharmacists by Community Pharmacy West Yorkshire and social services. All greatly valued the work of two PLWLD who collaborated with the trainers and involved themselves in

[32] Tragically, the lead person in setting up the Making Time project died unexpectedly before the evaluation had commenced.

helping to model some of the many challenges that community pharmacists may have encountered in practice with this heterogeneous group[1]. As Richard suggested, *'we need to keep training (provided for pharmacists) under review'*.

There have been several studies undertaken in the last two decades in pharmaceutical[33], medical[34] and educational practices[35], concerned with obtaining some measure of the extent to which there may be a transfer of learning gained from an initial training episode, such as Making Time. Generally, the findings from these studies point to the very low probability of the transfer of learning gained from an initial training episode into working practice – even when the presentation of ideas and their modelling of practice scenarios in the initial episode of training are regarded as being of good quality (as in this case)[36].

Transfer of learning from the initial training episode into on-going practice at the workplace was poor and the reasons were 2-fold. Firstly, training was held a considerable time before the service started so community pharmacists' recall of the events was low. Secondly, there was considerable work required in scaffolding support for practitioners in moving from gaining much 'at hand' largely inert information at an initial training episode and transforming that into 'ready-to-hand' equipment that practitioners make skilful use of in their practices[37]. 'To-hand' equipment, (recall), was hardly noticed by its participant community pharmacists. Listening to community pharmacists it became obvious that they each felt they were moving onto uncertain grounds in working with PLWLD in their practices.

[33]Linda Argote, Paul Ingram, John M Levine, Richard L Moreland (2000) Knowledge transfer in organisations: Learning from the experience of others, *Organizational Behavior and Human Decision Processes*, 82(1): 1-8; Nina Katajavuori, Sari Lindblom-Ylänne, Jouni Hirvonen (2006) The significance of practical training in linking theorereticall studies with practice, *Higher Education*, 51(3): 439-64

[34] Timoth T. Baldwin, J. Kevin Ford (1988) Transfer of training: a review and directions for future research, *Personnel Psychology*, 41(1): 63-105; Alan M. Saks and Lisa A. Burke (2012) An investigation into the relationship between training evaluation and the transfer of training, *Int J. Training & Dev*, 16(2)118-27
William C McGaghie, S Barry Issenberg, Emil R Petrusa, Ross J Scalese (2009) A critical review of simulation-based medical education research: 2003–2009, *Medical Education*, 44(1): 50-63

[35] Richard A Schmidt and Robert A Bjork (1992) New Conceptualizations in Practice: Common principles in three paradigms suggests new concepts for training, *Psychological Science,* http://journals.sagepub.com/doi/abs/10.1111/j.1467-9280.1992.tb00029.x

[36] Bruce Joyce and Beverley Showers (2002) Student Achievement through Staff Development, *National College of School Leadership*, 1-5

[37] Kevin J Flint, Sue Jones, Saira Ali and Hadar Zaman (in preparation) What has remained hidden behind the effective use of coaching: Turning inert knowledge into skilfully used equipment, *Int J. of Education, Learning and Development*.

In reflecting more generally about his training Gerald noted,

> *'I don't think we always get the training…a lot is expected of us without necessarily having the training input at the beginning but I think we're quite adaptable'.*

Although understandably the community pharmacist, Riley, could *'not remember well'* much of the details of the initial training given, following the training episode he did recall '*logging on to the 'Pharm-outcomes' to look at what was required'* in order to gain clarity on what he would need to do in his practice in working with PLWLD. Riley reflected:

> *'It (the project) was very open as in terms of what you would want to do with patient as it's based on what they (PLWLD) want and what sort of goals they wanted to set and then to help them. I suppose it's quite hard to train in anything specific because it was so open'.*

Not surprisingly, in fact, only one of the community pharmacists, Rex, had retained any memory of the initial training episode. He spoke of *'an evening session where Nigel came and talked us through it'*. In his perception *'it was pretty straightforward'*. Rex reflected, *'I don't think there was much training needed to be quite honest'*. Hopefully, by now Rex's position which typified the response received from other community pharmacists, has been challenged a little by this evaluation.

It was notable, too, that most of the stakeholder group had little to say about the need for training to include anything more than an initial episode prior to the launch of the project. It was also found that their responses to the issue of the training provided were generally more expansive than that given by the community pharmacists themselves.

On interviewing Rosemarie, one of the strategic leaders:

> *'Training was not about <u>how to deliver services but about understanding the client group</u> and understanding how to generate conversation with them as <u>they only take in so much</u>' (emphasis added).*

Her final comment, *'they only take in so much'*, revealed much about the assumptions made concerning just one-way communication from the professional to the PLWLD. Naturally Rosemarie placed emphasis upon the need, from a community pharmacist's perspective, for '*on-going support and feedback'*.

She added:

> *'People have to know they're doing a good job. People will only take in so much before they want to go and do something different. There is a need to support pharmacy team in delivering whatever they're delivering. On-going support, too. Make sure that people get feedback'*.

She reflected further:

> *'Having reference materials to go back to, so that you can refresh yourself about aspects of the training. Knowing what good looks like in practice, helps what's expected of the pharmacist'*

Here, whilst Rosemarie was suggesting, in the words of educationalists[38], *'scaffolding support'* for community pharmacists, it was interesting to note that the service also involved ongoing support for community pharmacists. This comprised of telephone calls and face-to-face visits to reflection on the progress that community pharmacists were making. Her earlier experiences as a community pharmacist had also made her acutely aware of the demands upon staff time that training makes upon pharmacy businesses. She suggested that if, perhaps, *'I was to start the programme again now I would include trainers' video recordings of what's done in the pharmacy'.* Rosemarie reflected:

> *'I think perhaps, giving them (pharmacists) a couple of hours in the evening where they come together and voice some of their concerns: that would give them a chance of talking with other people'.*

Therefore, it was no surprise at all to find that only five of the original group of 20 community pharmacists appeared to remain able to continue with the project. Given the complexities of the skills required, as suggested in this evaluation, then it

[38] Julie Radford, Paula Bosanquet , Rob Webster, Peter Blatchford (2015)

followed that there had only been a relatively small uptake of PLWLD in working with the pharmacies.

Indeed, it was a mark of community pharmacists' practices and their capacity for adaptation to innovation that there were a small but significant number of persons who gained some very real and life-affecting transformations from their work with the community pharmacists.

Esmé the GP and clinical lead on this project provided a notable exception that in her assessment *'the (initial) training worked well. There was feedback from the pharmacists. They felt they'd learned and were prepared to go forward'*. Esmé, also indicated that for her *'the case examples from the videos we used in the project really worked'*. She added, *'I think it gives them really positive messages. It also makes people think, perhaps, how they can do things a bit differently'*

She further elaborated in response to a question concerning the problems encountered in the project. From a clinical perspective, she noted the fact *'there are a lot of people out there with mild LD'* and Esmé reflected:

> *'They're leading completely ordinary lives, but they are not identified by any register. But they still have difficulty understanding medication and complying with lifestyle changes. And, I expect it is difficult for a pharmacist to deal with it'.*
>
> *Are they empowered enough to say, 'that person's got a learning disability'?*
>
> *I don't know how comfortable they feel about labelling someone with a learning disability. I know that many GPs don't feel comfortable. And, almost feel you have to have an IQ test to confirm. But, that's not the case. And you don't. And it's very hard to get an IQ test these days. So, I suspect that there are many pharmacists who did attend the project who saw people with LD. But were unsure. And that's a really difficult problem to overcome.*
>
> *We can't identify them because we don't know they exist unless they come to us. And, I think it's a lot to ask a pharmacist to take that on. There is a reason why they couldn't. You'd have to have sufficient training so that they could do that'.*

From this perspective, therefore, there was a significant risk that a number of persons with borderline/mild LD may simply have been missed as they had not been identified by any organisation. In this project carers and other healthcare workers identified PLWLD for inclusion in the project. It could be argued that community pharmacies, being much better placed to attract a wide range of customers, including those, not registered with borderline/mild LD, could offer even more support and signposting into formal services. As seen in the introduction, only around 20-25% of patients with borderline/mild LD are known to the health service.

Making Time; a Service for the Community

Executive Director, Rosemarie, spoke of a *'person-centred service'*. *'Making Time is not about providing a new service, it's about having time (and space) to provide services already offered by pharmacy'.*

Gerald (community pharmacist) also mentioned that as part of the project;

> *'some pharmacies run a weight loss programme, whereas others decided to run a combination of services'.*

At his pharmacy for Making Time

> *'we did an MUR as part of the initial assessment so everyone had an MUR and then the goal setting was individual. That was based on the people we were seeing individually'.*

Rex, laid emphasis upon the teamwork involved. He noted how, although

> *'the staff are pushed so that they have a lot on their plates they don't mind'.*

This returned us to an earlier point about how people must feel ready to undertake new projects, and the notion of readiness was at the heart of the structuring of clinical practice.

Interestingly, too, from Esmé's perspective as the lead clinician in the project, she had viewed it as a *'new service'* for PLWLD and laid emphasis upon the fact that persons with *'LD present as mild, moderate and severe'*.

It was noticeable that not one of the others involved in the project had given any emphasis of this categorisation of LD and others had recognised that the project had tended only to attract those with borderline/mild LD. There was an encouraging ethos of commitment from all community pharmacists to learn more which was pivotal to constituting a new service.

For the commissioner, Joseph, the development of Making Time was directed towards four outcomes:

- *'improving access to resources;*
- *improving the skills and ability of the pharmacist to engage with people with LD;*
- *improving health and well-being outcomes using community pharmacy; and,*
- *making community pharmacies more accessible'.*

Looking outwardly at other possible practices from the project, Richard (stakeholder), observed:

> *'They (pharmacists) want to contribute to the health and well-being of the public. The support structures that we put in place for Making Time really helped people to understand that'.*

This went beyond the service explored in this project and he understood clearly that the learning from the implementation of Making Time could bear fruit in other possible services.

> *'Some of the skills learned in this Making Time project will be transferable to work with other patient groups. You know – that breadth of looking at people holistically, and examining people's goals and what they want to achieve from treatment in ways that encourage them to say what they want to achieve from treatment'.*

For him, such possible development from this project *'would be great'*. Given the contribution to education in public health cultivated in this project, this always remained a possibility.

Making Time; Easy Read Leaflets

The production and application of the Easy Read leaflets, which had much wider use beyond the scope of the project, also provided a focus for collaboration between the GP and lead on clinical practice, Esmé, social services, the evaluation team at the University of Bradford, along with the community pharmacists. Gavin, who worked as a Senior Area Manager for the social services in Leeds remarked:

> *'I think the Easy Read information is brilliant...We were able to develop A4 size Easy Read leaflets with pictures. (We presented) much simpler descriptions of medication. How to take it. What it's used for.*

On reflection,

> *'Funnily enough. I'd really like you to record this – one of the very useful things it was for us was that it gave a mechanism for any new staff members that came to our organisation. Preparing them to work with people with LD. For people who had very little knowledge of psychotropic medication, and de-convulsant medication, for example, then Easy Read leaflets were a very valuable tool. It gave them an understanding of why people take the medication and what the side effects might be. There were clear instructions given.' Here was a spin-off benefit if you like.*
>
> *So, the Easy Read information was certainly very successful and it's something I continue to use now. Even though the project has come to an end'.*

For Ashton, who was a Service User Learning Facilitator, and based in the LD unit at the Leeds and York NHS Trust the issue of the Easy Read resources had been their significant impact in supporting practitioners and others in their work with persons with LD. Ashton reflected that for him:

> *'the key bit is how people use the project (resources) and how they in turn affect the interactions between people. Of course, we were looking to see if we could make pharmacies more accessible to people with LD by offering something that would enhance that relationship. And, build that relationship. So that people had a something that was useful to them in a more on-going way, even after the study had finished.*

Ashton then continued to elaborate a little in terms of his own specific service:

> *'We've been looking to provide resources which for the pharmacist helps them to become more comfortable in knowing they've got something they can offer to someone with LD. Consequently, it would affect their behaviour when it came to someone with learning disability'.*

Using the words *'more comfortable'* could be related to narrowing the communication gap between community pharmacists and PLWLD enabling more effective discussions and disclosures of messages. Easy Read had been a major success and its developed resources could be employed by other professionals.

Making Time; Caring for persons

Undoubtedly, too, a major success of the project revealed in this evaluation was in opening space for a small number of persons with LD in ways that encouraged them to make significant and sustained transformations in their lifestyles and radical transformations in their everyday worlds of practice.

Manifestly, the project began to provide a focus upon the success of HCPs in caring for persons. The provisional evidence from three community pharmacists involved in the project indicated some of the challenges involved in supporting and caring for persons labelled with LD.

Rex (community pharmacist) noted how the services they provided at his pharmacy were '*very successful for one lady'*. In response to the question of the extent to which the project helped to create this success

> *'I would have helped this lady if she'd have asked us in the first place, but the Making Time service gave us the opportunity to ask':*
>
> > *"What do you want to do," or:*
> >
> > *"What can we help you with."*
>
> *So, (presenting her with this service) just got that conversation going a bit quicker: that was brilliant and we also helped get her back into exercise. She*

did start exercising and managed to lose weight, but then stopped and we helped her get back into swimming and doing some activity.

The first thing we did was to help her stop smoking. She went down from forty cigarettes per week and has completely given up now. I mean, it took about six months or so. But, she was a very unique individual in that she'd already managed to lose loads of weight.

We also did an MUR with her and sorted some of her medication so actually ended up stopping some of her Parkinson's med's which has stopped her restlessness. I think she was a little bit over-prescribed on Parkinson's medication so she is a lot less restless now. Consequently, that particular lady really benefited from the Making Time service'.

This success, of course, in turn challenged many patterns of data presented in the literature as described in the introduction where there were guidelines and documents around generic issues but none with a focus on the challenges of working and communicating with PLWLD. As noted earlier in this report, Rex's actions in caring for *'this lady'* demonstrated that it is quite possible, given the appropriate clinical support, as Richard (stakeholder) indicated in conversation, *'to create the space and the time'* for persons with LD to transform pivotal aspects of their own lives; each person transforming their own world of everyday practice.

Returning to Rex's obvious success in working with PLWLD, he expanded further upon other persons he had supported through Making Time.

'Everybody else we made sure they got a flu jab or we tried to make sure they got a flu jab. I'd say maybe 5 out of 8 got a flu jab so over half so that was something...Other than that, we tried getting people back into physical activity or sport because a lot them did physical activity to start with, but then it disappears off the agenda really. Because it's so useful for their social circumstance as well. So, we tried to make them get back into that, and a few did improve but as I said we struggled with 3 or 4 getting them back in'.

In Rex's words, *'having the Making Time service gave <u>us the time</u> to come in and sit down (with these persons) to discuss things' (emphasis added).*

The gift of time and space for this community pharmacist had been pivotal in creating also the necessary professional time and space for him to work with his clients, in his clinical capacity as a caring community pharmacist. Gerald (community pharmacist), was working as part of a team in a community pharmacy with PLWLD also met with considerable success. He noted that they had been able to '*get over twenty patients signed up'* for the project. This was a major success for the project reflecting both their team-based approach to the care given to persons with LD and the juxtaposition of a local care home.

PLWLD who signed up at Gerald's pharmacy were based in a local home which supported independent living for this heterogeneous group. They each attended, with support from their carers and Gerald spoke about the challenge of getting this group to attend the pharmacy in the first place. Ordinarily, he explained, the pharmacy supplied persons at the home with a *'tray of medications'* and this gave them little motivation to attend. Consequently, one of their goals set for these PLWLD at the community pharmacy had been *'to come for an appointment'*. In Gerald's mind for most of this group *'that was quite a big achievement for them'*.

Other goals Gerald's pharmacy set for particular *'patients'* included *'weight loss'*, *'smoking cessation'* and *'socializing'*. He recognized that the goals had to be negotiated and tailored for each person. *'Probably about seven stayed working with us'*, said Gerald. *'They just liked to come in and have a chat – it was something good for them'*. By consideration of the world of practice of persons in this situation, this evaluation could begin an understanding of the importance for persons of being-with others in a place where they each *'feel safe'*. Gerald recalled that being with others in the pharmacy and chatting *'made a difference to their confidence and (helped) them to feel comfortable with the pharmacy staff coming into the pharmacy'*.

Gerald's pharmacy, then, had become a safe place for this heterogeneous group of persons with LD. He observed that *'it made a massive difference to them'* in terms of their express confidence and whilst not medication-related was health (mental) related.

On further reflection, too, the successes for the persons with LD themselves arose from the service of 'lived time' created by their community pharmacist together with creating social, disclosive *'lived'* time and space. Herein lay another success of the project.

Making Time; Contributions to public health and education

Two community pharmacists were very positive about the pivotal role of Making Time in promoting public (health) education concerning the use of community pharmacies. Rosemarie indicated that it *'fits perfectly with our role (as community pharmacist) in promoting public health'*. She elaborated:

> *'Many goals for our clients in Making Time were very simple. For example, there was one client who was drinking a large bottle of coke every day. And pharmacists could explain to her some of the risks and dangers to her health: rotting her teeth; her weight; the caffeine levels. Following that conversation, she drank much less coke. She received a massive health benefit'.*

Equally, Rosemarie was very clear on why the project had been successful in promoting public health with PLWLD. She spoke of *'the pharmacist (being) able to talk them round and have a more detailed conversation about some of the issues involving public health'*. Unconsciously, here Rosemarie gave voice to the community pharmacists' emerging educational and pedagogical aspects of public health. Everyone involved in the project agreed that public education constituted a powerful and important dimension of the Making Time project.

Richard (stakeholder) could place in context the contribution of the project to public education:

> *'We've seen, over the years, pharmacists making tremendous advances and contributions in supporting healthy lifestyles and healthy living through harm reduction protocols, supporting people to lose weight, doing walking clubs, getting people active… We've seen pockets of these. The more we do in systemising these in the work of pharmacists, the better we do for local populations. You know, seeing pharmacies as the hubs for health and wellbeing, using the estate, the resources and the skills we already have. You*

know, pharmacists with a five-year Masters' degree trained in nearly every high street in the country is just a phenomenal asset we need to do more with.'

Similarly, Joseph (former stakeholder), was clear that community pharmacists made a significant contribution to public health. He noted how:

'…a lot of people see them (pharmacists) as people who dispense medications. But, I think they have a different skill set and a different knowledge set, really. I think there's been some really interesting feedback from the pharmacists, more than the doctors. And, I think pharmacies give really good messages… they're in the high street, they are a great place if you want to send out some positive messages about looking after yourself. I mean, they are well placed for that' (emphasis added by the authors reflecting the uniqueness of geographical location)

Consequently, Joseph's unconscious use of educational principles constituted in his discussions, expressed how community pharmacists and their teams care for others, and suggested a pedagogy of public health concerned with caring for the person/persons within local communities. It was entirely consonant with the growing understanding of health that had been cultivated by this project.

All community pharmacist participants agreed that community pharmacists/pharmacies had a significant potential role in promoting public health. What remained was a question for further research of just how effective the different pedagogies of public health are used to engage PLWLD and more generally with other persons.

Kiren (community pharmacist), wished for community pharmacists to be able to take a bigger role in public health. But, whilst he recognised the importance of gaining extra time with clients in the project, more generally he acknowledged that in *'spending more time in being people facing, I need more ACTs*'

Certainly, as one of the individuals who worked closely with the pharmacies involved in the project and who took a lead in developing the Easy Read leaflets, Gavin, was

in no doubt that the Making Time project had made community pharmacies *'more accessible'* to the public. For him the project *'raised awareness that pharmacies are more useful than maybe they have been perceived before'*.

Similarly, as far as Ashton (significant contributor to the development of Easy Read leaflets), talking about community pharmacy with groups with LD had never happened before. Nor, it would appear had there been any consideration given, before this publication, to the pedagogies that best promote public health for PLWLD. Ashton reflected:

> *'Now we've been to the lead people and we've talked to them about what you might want to use your pharmacy for. What you might get out of it. We know that a number of people have gone. And they have seen their pharmacy in a different way. So, we certainly have had some kind of impact in terms of people's understanding of what a pharmacy might be able to do'.*

Pharmacists were keen to discuss their role in public health and all of them felt that projects such as Making Time represented the future direction of community pharmacists' role in providing services to patients and moving away from a dispensary-based role.

> *'…Its a brilliant service (MURs) but there is too much focus on 400 as a target…Although they don't make it out to be a business target that's ultimately how it comes across that you need to do 400 or you're not performing'.*

Community pharmacists were positive about this, though many still spent most of their time in the dispensary. Stress, time constraints and the current funding model based on quantity rather than quality, were also mentioned by the community pharmacists in this study (Jacobs *et al.*, 2013). This reiterates the need for transformation in the pharmacy profession to ensure consistency as well as change by community pharmacists themselves to be more service-orientated.

Rex noted that often community pharmacists are often involved in a circular argument

'…pharmacists always moan that they hate checking scripts and then when you ask them to do another service they always say 'oh I haven't got time because I'm checking scripts all the time'…if you think that… then you aren't really doing your job properly'

Whilst it was acknowledged that service provision was a balance between target-driven *'clock time'* and patient-driven *'lived-time'*, this was no different to other HCPs.

In summary, then, all the professionals involved in this project remain entirely driven by a powerful moral force that directed each of them in their own particular ways to move towards improving the care given to PLWLD.

Making Time; A Model for Understanding of PLWLD

The conversations with patients uncovered interesting findings for the project and in order to make sense of what happened, each patient who was interviewed formed a case and from extended reviewing of the data from these conversations, a proposed model was developed to help to understand the meaning of these conversations. The view at this stage was to better understand how to support building effective relationships with PLWLD and their community pharmacists. For PLWLD in this study, their understanding and expression of their world, which was sought deliberately by this project, was to bring their communication practices into the research consciousness this evaluation could seek to understand their world of practice. This service enabled PLWLD to engage and interact more closely with their community pharmacist and improved their health. This pilot project may support the development of a more sophisticated understanding of how the whole concept of creating time and space through a funded service could be developed for future projects. They all had their own unique ways of giving expression (equipment); each in their own languages, to what had mattered for them in their own terms. For many this amounted to using an unpredictable mixture of formal and informal signs, sounds and silences, incomplete sentences, and various words that had significance for each of them.

The logics of practice that follow in this section were developed by researchers with competence in language. Such logics gave a useful starting point for developing a systematic analytical framing in which listening to *'persons'* remained possible. But, in listening to the *'person'* in each case, in practice it there was a need to keep in the foreground the requirement that such listening to the other involved learning afresh in each case, aspects of the others' languages.

Making Time; Case Studies of person's experience

The results of each person's interaction with the researcher were presented in the form of two groups of case reports. Qualitative research and previous published research had little to offer in terms of working with PLWLD to evaluate their views on a service. Therefore, to explore the methodological approach, two preliminary cases were reviewed, not related to Making Time to allow the methodological framework to be developed; this is Group 1.

Table 2: Contribution of PLWLD to the Research

Group 1	Group 2
Case 1; Jonathan's Mumble Orchestra	Case 3 – Beth's practice in making history
Case 2; A mother's move to open space for her son	Case 4 – Dorothy and Elsie's practice: Habits, limits and lacuna
	Case 5 – Scott's practicing, feeling and wording

Group 1

Making Time; Case 1 - Jonathan's Mumble Orchestra[39]

The 'Mumble Orchestra' was the name of one game played by participants at Artshape. In the game the leader makes various signs with their body, and the other participants must follow in exactly the same way. This was a person living with severe LD and was used as a formative case to help the researchers to understand more about the efficacy of approach to analysis of Making Time and to refine the known facts so far. In order to support these PLWLD, a mumble orchestra had been developed where one of the participants would lead as a conductor and others would

[39] This preliminary case was created with help from Mary Brazil (Art Therapist) who had worked with an organisation called Artshape in Sheffield.

follow the movements and sounds of the conductor. This highlighted the significance of language that didn't involve words and the informal visual signs and practice required. From observation, Jonathan had become animated and was enjoying himself and expressing himself with others mimicking, led to him starting to creating his own language of communication; informal and visual. By receiving feedback from other participants, he became more confident and had a mood of excitement. A number of conclusions were made from this case:

- There was always the requirement to ensure that the *'person'* was in a '*mood of readiness'*[40] to become engaged with knowledge or information; and,

- There was always the challenge of encouraging the *'person'* to transform inert and *'at-hand'* key information/ knowledge into *'ready-to-hand'*[41] *'equipment'* they could use (almost without noticing) in their everyday world of practice.

Making Time; Case 2 – Mother and Son

This formative case was created from information presented on Mencap's website featuring one mother who was concerned about the labels given to her son by professionals. It was chosen as it had not been possible to involve any family members in the research and could be an opportunity for future work. The mother had unconsciously been an educator for her son and the love she gave her son opened up disclosive space for them both. She had accepted him for what he was and enjoyed what she had rather than trying to put a precise label of LD upon him.

Making Time; Group 1 Reflections

These two formative preliminary cases illustrate what became possible to uncover from persons' various practices. Both cases put a spotlight on:

- The capacity of one person, albeit ordinarily labelled with LD, who was capable of sophisticated and nuanced practices involving the use of informal body language;
- The capacity of one mother, whose son had been labelled in a similar way, who found ways of opening space in which her son could be himself. Creating

[40] Mark Wrathall (2012)
[41] John Richardson (2012)

such social space for the mother involved the simple method of not using formal labels generated by professionals.

In focusing upon the use of signs in their worlds of practice, it became obvious that each person constituted their own identity in the differences/deferrals opened by their work/play with signs. From the evidence presented it was impossible to understand what the practices involved meant for the young men in each case. Provisionally, indications from Jonathan's facial expressions, was that involving himself in this game and so interacting socially within a community, meant a great deal to him. The mother-son relationship was presented on the website appeared to constitute a community of just two persons.

Making Time; Case 3 - Beth's practice in making history

This opening case from the Making Time project was generated from a person labelled with mild LD, Beth, who worked with her carer, Naomi. The interview, which generated the data for this case, was conducted at Beth's home, on the West side of Leeds. She made skilful use of her available resources using her own body language and was very careful to give expression to aspects of what was happening in her working with the community pharmacist.

She confirmed *'we (beth and her carer) were going there every month'*.

Beth continued *'we have a chat. He's a friendly man. He winds me up. Tyler says, 'not you again'!* (emphasis added by Beth).

Beth responds. Laughing. *'I tell him'. 'If you're going to be like that. I'm going to change my pharmacist'!* (emphasis added by Beth).

This expression of humour and disclosure spoke volumes about Beth having developed a comfortable relationship with her community pharmacist Tyler. His ability to empower Beth deserves further research and has assisted Beth in her readiness and willingness to visit her pharmacy. Beth's daily routine practice was structured around four episodes of medicine taking and she interrupted the interview

at one of these points. As a result of working with her community pharmacist Beth had stopped smoking from 20 per day in 10 months. She also remarked:

'I get lots of pain from arthritis … we're going back to Tyler. He'll help me'

This clearly indicated the trust in the relationship that had developed over 10 months; it had been cultivated and sustained between them and others and deserved further work to investigate how this happened. Additionally she had started swimming and had organised herself for a sponsored swim.

Making Time had created additional resources, support and advice from her community pharmacist to make significant and sustainable transformation in her own lifestyle and world of practice. The role her carer played was pivotal to her continued engagement and their relationship was based on a variety of nuanced non-verbal languages. She had met all her targets given to her by her community pharmacist.

Making Time; Case 4 - Dorothy and Elsie's practice:

Dorothy and Elsie were labelled with mild LD. They enjoyed each other's company and spent much time together. They were interviewed together, with their carer (Sue), who had only just met them for the first time. They lived in a home on the West side of Leeds, where they received full-time support from a group of professionals. The researcher continually sought to sustain a conversation with Dorothy first and then Dorothy and Elsie together. This was also assisted with Sue.

When asked whether she took medication Dorothy responded *'No'*
'You do take your tablets don't you' Sue added
Dorothy *'Yeah. M, mm, morning tea and bed'*

Upon reflection, it was clear that the earlier question about medication was not part of her vocabulary whereas the word tablets were. She associated her tablet-taking behaviour around routine of daily events just like Beth. This was such an important point about working with persons that a common language for all patients should be explored to ensure common and mutual understanding regardless of whether it was

verbal or non-verbal. As the interview progressed, the sense of friendship and community between these two friends was clear. The researcher also realised during the interview that both friends had their favourite place to sit so had to move seats; again a small nuanced point however, extremely important to the friends.

Making Time; Case 5 - Scott's practicing, feeling and wording

Scott was labelled with mild LD. He alone wished to talk with the interviewer without his carer present indicating that he wanted to be seen as being independent. He lived in the same home as Dorothy and Elsie on the West side of Leeds, where he received full-time support from a group of professionals. The researcher was greeted with a welcoming smile. Scott had made effort to lose weight assisted by visits to the local sports centre to go to the gym and swim whilst working with his community pharmacist. He did not have a formal language beyond bodily movements and many facial expressions. He had great difficulty in expressing himself in English. Scott confirmed, just as Dorothy and Elsie had, that he took his medicines at *'breakfast, dinner-time and tea-time'* with daily events structuring his routine. On reflection of the interview, the researcher described that it would have been interesting to explore Scott's feelings and how he expressed himself which was not achievable in a one-hour interview. For example:

'Did you like the pharmacist?'
'Yes. I did'. (silence)
'Did the person talk with you?'
'Yes'. (silence)
'What did this person say?'
'Ah… questions.' (silence)
'Were their questions helpful?'
'Yes'. (silence)

The silences were approximately one second long and were significant in his method of communication. The interviewer sensed that Scott wanted to communicate more but he simply did not have the words. He attempted to use his body language just as Jonathan had. Silences, the researcher concluded were to extend hospitality to their interaction and giving his lived time to the conversation. Scott stood up and

looked towards the door to indicate that the interview was over; another clear non-verbal sign.

Making Time; Group 2 Reflections

It became clear that each of the persons involved in these cases, whilst obviously remaining relatively limited in their capacity to use the English language, were all in the own ways able to engage in a multiplicity of sophisticated and nuanced practices, when account was taken of their innovative use of informal signs and body languages. All three of these cases put a spotlight on the very wide range of capacities for action presented by the participants;

Two of the cases revealed the extent to which Beth and Scott in their own very different ways were moving to transform aspects of their own everyday worlds of practice. Both cases also provide provisional evidence suggesting that Beth and Scott are moving to make their own histories in the ways they are continually working to transform aspects of their practices – pivotal to these transformations, had been the work of community pharmacists and their teams;

For Beth, the relationship she has obviously developed with her community pharmacist, her 'carer' and other support professionals, would appear to have given her confidence and the expectation that she can continue to develop aspects of her own practice in ways that assist her in maintaining and improving her own health. Scott, too, would appear to have gained confidence, and the sense of readiness to work on further improving his own health based on regular exercise, reflecting in some way his relationship with his community pharmacist. Whilst not so obviously concerned with fitness and exercise, Dorothy and Elsie's case reveals just how important remained their mutual support and friendship for each other. Moreover, they were also both alerted to the importance of the medications they had each been prescribed. Dorothy and Elsie's case is important in that it highlights there is no 'one-size-fits-all-approach' to matters of health.

Their own express meanings from being involved in their various practices have enabled some indication that in making meaning for themselves in their own lives

Dorothy and Elsie's understandings and what comes to be regarded as important for each of them is manifestly very different from both Beth and Scott.

On reflection, from the existing data, the clarity and the various meanings persons developed of health were unable to be uncovered within any clarity. It may be concluded that what had become meaningful were the evaluative measures taken of weight loss, of diet, of stopping smoking etc., used in the medical model as it stands. It may indicate that there remained a vital dimension of the intelligibility of human existence; namely, in moving to enhance and improve each person's various capacities in refreshing, re-energizing and revitalizing their own existence[42]. Herein remains an understanding of health that complements the medical model.

Interpretation of Findings

Models of practice

It would have been easy, therefore, in opening discussion upon the qualitative results from this project to remain focused upon individuals with LD. But, as suggested earlier, the many layers of national cultures along with the layers of localised cultures grown around this Making Time project, which all set out to represent persons in their community settings.

These arose from consideration of the dominant style of organisation used in working with individuals/people with LD. The dominant style of organisation that emerged from the literature, in terms of cultural layers created with the expectation of has been mirrored, in the localised cultures grown around the Making Time project. In that way, various questions emerged from consideration of the style of organisation gifted us with a series of questions that could be employ in critical examination of the findings from the qualitative study.

[42] Kevin J. Flint, Sue C. Jones, Hadar Zaman and Saira Ali (in preparation) Towards a critical reading of Gadamer's discussion concerning the concealment of health for pharmacy practice in the community: Re-thinking Frederick Svenaeus' Hermeneutics of Medicine and the Phenomenology of Health, *Medical Health Care Philosophy* and *Journal of Pharmaceutical Health Care and Sciences*.

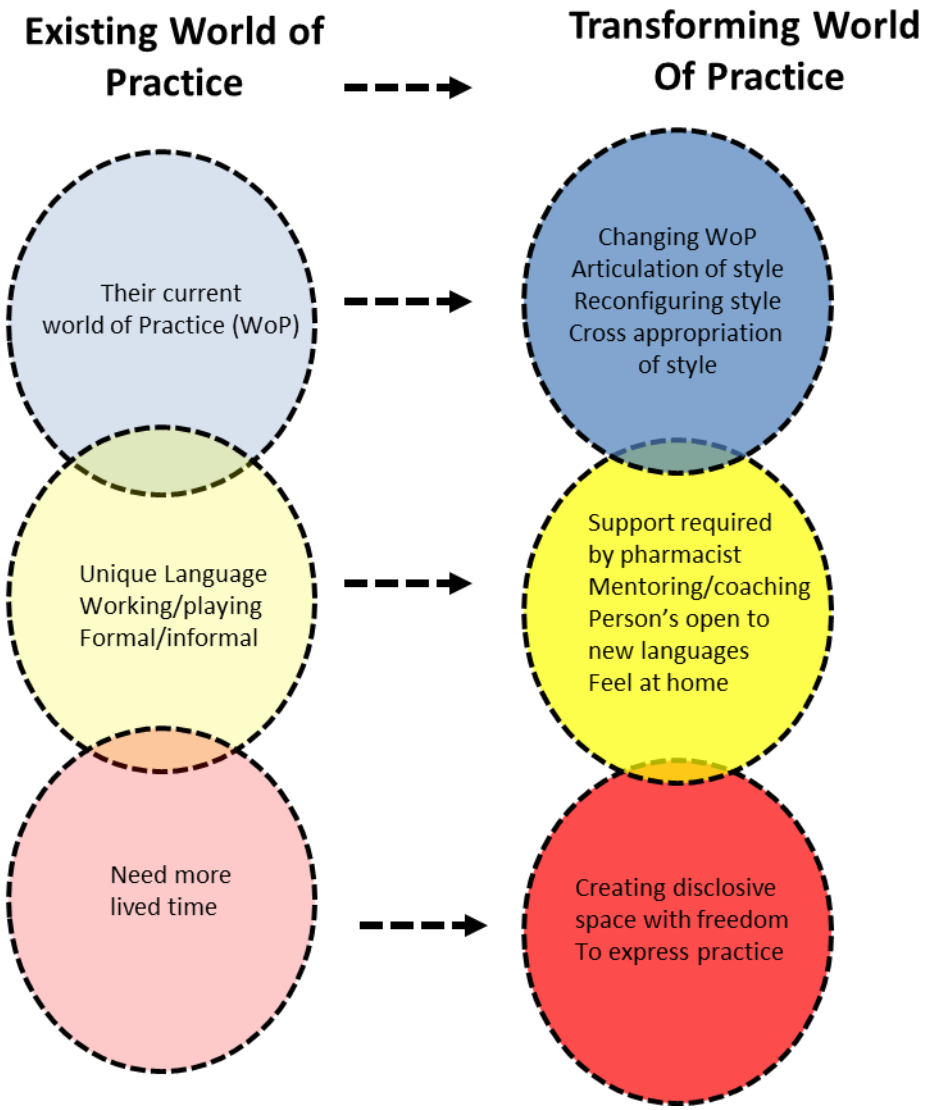
As suggested by the image of the individuals, in this traditional model the individual had always been conceived as open to the possibility of exceptional behaviour that did not fit the pattern exhibited by the great majority.

Clearly, in moving to discuss the results from the qualitative study there was a desire to look forward at the style of organisation that could be further explored in working with persons in their various communities of practice. Fortunately, despite the very limited outcomes from the patients themselves, each of the patient's practices, along with each of the community pharmacist's practices, involved in the project, have suggested a provisional model concerning persons' making-lived-time for themselves.

Discussion of Making Time; Transformation of Practice

Through extensive revisiting of the findings, the transformation of clinical and communication practice can be reflected upon by considering the PLWLD and community pharmacists' existing and transformational styles of practice.

Figure 6: A Suggested Model for the Transformation seen by PLWLD when working with their Community Pharmacist

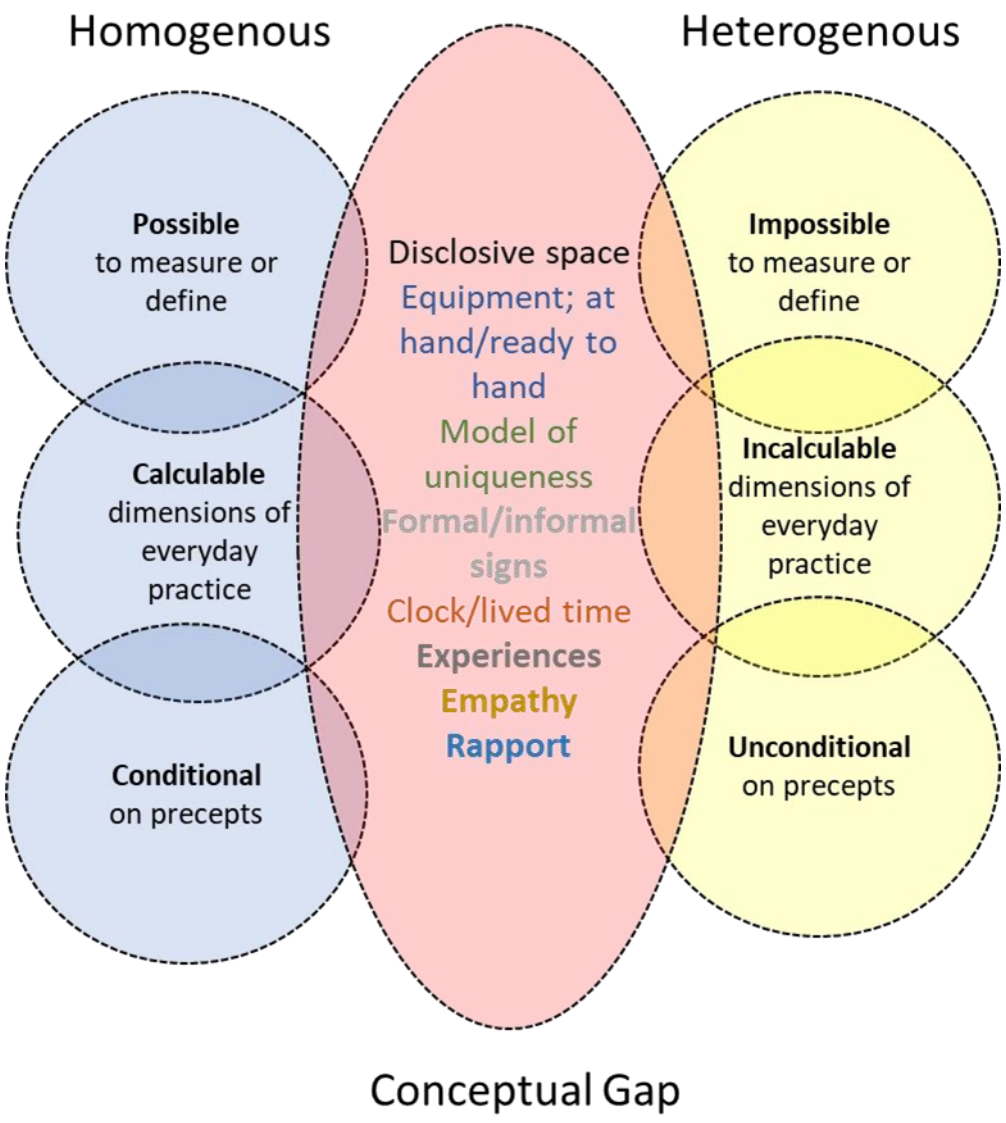


Making Time required both PLWLD and their community pharmacists to build successful relationships to communicate between each other, at an understandable and translational level, to enhance care. The figure about tried to capture some of the elements of transition.

In moving to discuss the findings, it was vital to look back at the style of organisation (national and local) originally envisaged for the Making Time project. In radical contrast, looking forward at the style of organisation required to support persons in their making-lived-time in their various communities of practices; persons who endure the daily experience of living with the label of 'learning disabled'. The aim of

looking forward, therefore, was to uncover from the qualitative data the basis for understanding more concerning just what is required in-order-to open space for persons; space in which they each have the possibility of becoming empowered in their own personhood to work on maintaining and improving the quality of their own health.

Figure 7: Patient Care in Pharmacy; dimensions at play



From the figure above, this re-presents reflection of the findings. Having explored areas where the project was very successful together with limitations of the research it opened a conceptual gap for working with patients *'living with'* long term conditions. On the left-hand side in blue could be a representation of the current medical model where things are objective and factual. As have been seen from this evaluation, PLWLD require much more engaged person-centred, tailored approaches as represented on the right-hand side; subjective factors. In the middle are some of the concepts, theories and ideas emerging from this evaluation that deserve further investigation to really engage in true person-centred care.

By attempting to uncover the basis for modelling a person's health in ways that extended beyond the scope of measurement, and of medications. There was curiosity to uncover whether such a model was possible and what it might mean in terms of extending understandings of health, healthcare, interactions person-person. In the longer term, the aim of these discussions was to open space for new understandings of health that complement and may be used in parallel with more standard medically based therapies. In moving towards that point, a desire to open the basis further research, which may be used in helping persons, each in their own style of language, to understand more about themselves and their own health in their own terms.

Conclusion and Recommendations

This evaluation should have been straightforward and simple, do a few interviews, transcribe and present. What occurred was not so simple and this research would like to posit the development of a novel approach to interviewing PLWLD with an attempt to make sense of their worlds of practice. In doing this, it is hoped that these persons feel that justice has been served in the interpretation and their complex and nuanced languages they articulate in their everyday practice. Clearly, morbidity and mortality rates together with the lack of identification of the population of persons *'living with'* a learning disability means more focus is required. By studying this group of persons, this could lead to development of more specific and tailored person-centred rather than population centred care.

This study began with the aim of investigating the work of community pharmacy professionals in health care in *'Making Time'* for persons. In working with PLWLD, from this evaluation several provisional conclusions with wider ramifications for the approach to care given by professionals to patients suffering from a range of chronic conditions can be posited

- The Making Time project and its evaluation has opened new disclosive space for some PLWLD, enabling them to revitalize, re-energize and radically refresh aspects of their own lives in moves to maintain and improve their own health.
- It has opened further reflection upon a complementary model for health care, which focused upon not only the existing grammar of medical practice, pharmacy practice, and other aligned health care practices, but also complemented this focus with concerns directed towards the languages and worlds of practices of persons; each with their own style of practice, living in their own unique communities of practice.
- It has generated new knowledge and in doing so, opened a new language for the practice of caring for chronically ill patients that provides the basis for further evaluation of a similar service rolled-out for a year for other persons living with chronic conditions with the aim of examining ways of further improving the care given by professionals in the health service[43].

[43] See also Twigg et al. (2019) The pharmacy care plan service: Evaluation and estimate of cost effectiveness. *Research in Social and Administrative Pharmacy*. 15:1:84-92

- It has generated a range of 'Easy Read' materials, which health-care professionals could use in supporting communication with their patients and these gained their own momentum as *'ready to hand'* equipment.
- It has indicated the potential, the energy and the moral commitment of professionals working in pharmacy practices for developing their support and care for patients in the community. All the professionals involved in this project remained entirely driven by a powerful moral force that directs each of them in their own ways in moving towards improving the care given to persons with LD.
- The knowledge of community pharmacy practice provided a clear focus upon the styles of practice reproduced daily by chronically ill patients in their worlds of practice, and it has created a language and a framing for mentoring and coaching professionals in further developing their work in caring for, opening space for, and possibilities for, chronically ill patients.
- It also opened up critical reflection of approaches to *listening to* and in *opening lived-time* for persons in their own practices.
- The knowledge created additionally allowed reflection of a new language of communication in which to evaluate health of persons in their own unique communities of practice, in ways which complement the current medical model.
- Various cultures were identified as factors affecting the interactions between PLWLD and their community pharmacists. The Western culture of 'clock time' needs to be tempered with other cultures of 'lived time' to work with PLWLD or other chronic conditions. By helping patients be understood was a vital dimension cultivating and sustaining the health of patients and the trajectory of Making Time.
- The terminology around dis-ability implies something is missing and whilst the Equality Act 2010 makes a move to removing some of the 'what's missing' dialogue however, there are great strides still to go.
- Despite the very limited outcomes from the patients themselves, both each of the patient's practices, along with each of the community pharmacist's practices, involved in the project, have suggested to us a provisional model concerning persons' making-lived-time for themselves.
- Finally, the research opens up time and space for further critical reflection upon understandings of the world of each person's practice within their own community setting.

Future Work

In summary, therefore, there remains considerable scope for future work in developing this project for chronically ill persons in a range of community settings. Several projects for further research have been suggested from this evaluation; not least:

- *Mentoring and coaching of health care professionals in developing their practice of caring for chronically ill persons*: The model of practice developed suggested several avenues of research focusing upon improving the quality of mentoring and coaching of health care professionals;
- *Caring for the person*: Additional research is required in-order-to uncover and to characterize how to make further transformations in team work in the community directed towards improving the care given to chronically ill persons. The cases described have illustrated how PLWLD communicate and it would be useful to uncover more about informal languages used by persons and how they give expression to the practice of their lives and their identities.
- *Understanding more about the transformation of person's practices*: Further research is required in-order-to characterize how community pharmacists working with other professionals can work to transform persons' styles of practice in the community.
- *Exploring and examining ways of opening space for persons in refreshing, re-energising and revitalising their own worlds of practices within their own communities*: Further research is required in-order-to understand and to characterise concretely how community pharmacists' and other HCPs work in the community in opening space for persons with chronic conditions, where they become energised in different ways to refresh and revitalise aspects of their own practices. Observing successful community pharmacist/patient interactions could help to explore the extent that community pharmacists could transform aspects of their own and person's practices.
- *Exploring and examining public health and NCD in PLWLD*. While several studies have shown that it is possible for specific interventions to create a sustained effect in helping people to stop smoking. Yet, not one of these studies has sought to examine the particular challenges involved in working with PLWLD[44]. National Institute for Public Guidance[45] available on this issue, makes

[44] Biomed Centre: Pilot and Feasibility Studies – Smoking Treatment and Optimisation in pharmacies (STOP): a cluste4r randomised pilot trial of a training intervention, https://pilotfeasibilitystudies.biomedcentral.com/articles/10.1186/s40814-016-0120-9;
Action on Smoking and Health, ASH: Quitting smoking made easier as high street pharmacies offer NRT on the NHS http://ash.org.uk/media-and-news/press-releases-media-and-news/quitting-smoking-made-easier-as-high-street-pharmacies-offer-nrt-on-the-nhs/;
C+D What's the best way to help patients stop smoking? https://www.chemistanddruggist.co.uk/feature/how-should-pharmacists-help-patients-quit-smoking;
Pharmacy Magazine: Smoking cessation – If it ain't broke… http://www.pharmacymagazine.co.uk/smoking-cessation-if-it-aint-broke

no mention of the challenges involved with PLWLD. When optimising medication for patients, none of the articles mention PLWLD[46]. None of these articles described the issues involved in helping PLWLD to move to an improved regime of medications. Even the GMC advice, *Good practice in prescribing medicines and devices*, makes no mention of the challenges of working with PLWLD[47,48] Indeed, in *Psychology Today*, Dr Graham Davey (2014) observes also that drug prescriptions for persons with mental health problems continues to rise. He notes that as many as 57% of people with mental health problems are being treated solely with medications without any form of psychotherapy'[49]. Again, however, there is no mention of the special challenges involved in working with persons with mental health problems who are themselves disabled in their learning.

[45] Hayden McRobbie and Andy McEwen (2005) 'Helping smokers to stop: advice for pharmacists in England', NHS National Institute for Health and Clinical Excellence, RPS, Pharmacy Health Link: http://www.ncsct.co.uk/usr/pub/helping-smokers-stop-guidance-for-pharmacist-in-england.pdf

[46] Scott Cohn (2007) The American Greed Report: Is your doctor prescribing too much medication? Watch for the signs. Corncast National Broadcasting Corporation, CNBC https://www.cnbc.com/2017/03/10/the-american-greed-report-is-your-doctor-prescribing-too-much-medication-watch-for-the-signs.html;
SE Smith (2016) War on prescription drugs: what if you depend on the opoids to live a decent life? *Guardian*, 12 July https://www.theguardian.com/us-news/2016/jul/12/prescription-drugs-what-if-you-depend-on-opioids-chronic-pain;

[47] GMC (2013) Good practice in prescribing and managing medicines and devices, http://www.gmc-uk.org/Prescribing_guidance.pdf_59055247.pdf;
Hannah Roberts (2016) Research Briefing: Misuse of prescription and over-the-counter medications, National Assembly for Wales, Research Service http://www.assembly.wales/research%20documents/16-039%2016-039%20-%20addication%20to%20over%20the%20counter%20prescriptions/16-039-web-english.pdf; NHS Choices (2014) Almost half of all adults take prescription drugs, http://www.nhs.uk/news/2014/12December/Pages/Almost-half-of-all-adults-take-prescription-drugs.aspx;

[48] Sue C Jones, Kevin J Flint, Saira Ali and Hadar Zaman (*in preparation*) Working with persons: Challenges for health-care professionals in the community, *BMJ*

[49] Graham C.L. Davey (2014) 'Overprescribing drugs to treat mental health problems: 10 reasons why drugs shouldn't be a treatment of choice for mental disorders', *Psychology Today*, https://www.psychologytoday.com/blog/why-we-worry/201401/overprescribing-drugs-treat-mental-health-problems

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