





# Making Time Interim Report

10.9.2015 - 16.5.2016



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## **SUMMARY AND RECOMMENDATIONS**

Making Time was introduced in September 2015 with the aim of improving health and lifestyle outcomes for people living with a learning disability through greater support from their community pharmacy. The service has been developed for people with learning disabilities to receive accessible community pharmacy services that are person-centred supporting a healthy and safe lifestyle. Patients are referred into the service, usually through their carer, although they can also self-refer or be referred by the GP. Once registered an initial assessment is arranged which discusses the patient's medicines (what they are used for and how to take them), lifestyle, health and well-being. Subsequently a series of further consultations support and encourage the patient to set and achieve goals, have discussions about their medicines or discuss issues important to the patient relating to their health and lifestyle.

*Making Time* is currently in its infancy. The project is constantly evolving as pharmacy staff and commissioners, with patients, determine the best way to deliver the service for the benefit of the patients it serves. To date 65 people have registered with *Making Time* and 26 have gone on to have the initial assessment, with many of these setting goals around their health and lifestyle. Goals have ranged from basic, such as setting a goal to attend the next meeting in the pharmacy, to more complex such as learning more about their Parkinson's medication and eating more healthily by understanding the content of different foods. The pharmacy staff have also provided reassurance and emotional support for patients and facilitated regular weigh-ins for patients trying to lose weight. Current data suggests that the initial assessment takes the longest of the series of consultations (approximately 25 minutes), with subsequent consultations being half to two-thirds of the initial consultation. The majority of consultations conducted have been carried out by a single provider. It is important to capture learning from their approach to enable the reasons for their success to be shared.

This report provides an interim summary of data to date and is intended to provide information to shape the ongoing service. Recommendations to support future delivery the service are outlined below:

#### Recommendations

- Learn from pharmacies who are delivering high numbers of follow up consultations and share good practice
- Explore the reasons why the number of patients followed up from initial registration is low and determine ways to increase follow up consultations.
- Explore General Practice as a route of referral
- Increase number of goals around exercise to support inactivity and weight loss
- Explore self-referral form people living with a learning disability in the community (not statutory accommodation)
- Explore referral from family carers
- Routinely review the goals set by patients to determine what further leaflets may need developing.

## **1** INTRODUCTION

Around 1.5 million people, 2 out of every 100 people, in the UK have a learning disability.<sup>1</sup> Learning Disabilities are many and varied and can affect a person in various ways. Learning Disability affects the way the individual understands information and how they communicate. This means they can have difficulty:

- understanding new or complex information
- learning new skills
- coping independently

People with learning disability are more likely to suffer considerable morbidity. They experience much higher rates of respiratory disease, epilepsy, dementia and Schizophrenia than the general population. The life expectancy for people with learning disabilities is less than for the general population. They are 58 times more likely to die before 50 than the general population.<sup>1</sup> Men with a learning disability die 13 years sooner than the general population.<sup>2</sup> The cause of death however is 4 times more likely to be preventable. These statistics demonstrate the huge potential to improve the health and wellbeing for those with learning disability.

Many of these patients will be prescribed medication for their long term conditions and will attend a community pharmacy to collect their medication. The *Making Time* project was introduced to provide people living with learning disabilities time with pharmacy staff time to discuss medication and how the medication may be optimised and also to improve health and lifestyle outcomes through greater support. The service enables people with learning disabilities to receive accessible and reasonably adjusted community pharmacy services that are person-centred supporting a healthy and safe lifestyle. The scheme is based on a year of care and delivers person-centred care through a series of consultations which meet the need of the individual. It follows a medicines use review (MUR) style approach supported by easy read information. This interim report reviews the data gathered through the service to date and makes recommendations to support the on-going delivery of the service.

# 2 AIMS AND OBJECTIVES

#### Aim

To report the initial progress of Making Time using data captured through PharmOutcomes

#### Objectives

- Determine the number of patients who have accessed different stages of *Making Time*
- Describe the demographics of the patients attending Making Time
- Describe the goals set and actions taken to date
- Determine the time taken to deliver each stage of the service

• Describe individual patient journeys through tracking individual patients using unique patient ID in PharmOutcomes

# **3** SERVICE

*Making Time* was introduced in September 2015. Expressions of interest were gained from 18 pharmacies in South Leeds and subsequently, 7 months later a second wave of 6 pharmacies were recruited in West Leeds.

Any patient with a learning disability who has consented to taking part in *Making Time* could be included in the project. Patients can be referred into the service via:

- Adult Social Care Learning Disability Team.
- Other social care providers within the area.
- Self-referral
- Carers
- The patient's GP



Pharmacy teams can also identify and directly recruit patients to the service through talking to any patients with a known learning disability about the service. Pharmacies displayed posters to advertise the service and displayed a *Making Time* sticker in their window.

Patients are invited to register with the scheme and have the scheme explained. Once registered an initial assessment is arranged which takes an MUR style approach to discuss the patients medicines, lifestyle, health and well-being. The initial assessment may occur over several consultations depending on the patient. During the initial consultation the patient's smoking

status, alcohol consumption (using the AUDIT tool), physical activity, weight, and BMI are captured, as well as the any issues with their medication.

Following this consultation the patient is assisted to set goals and then encouraged to return to discuss the goals set through a series of contacts (see figure 1). Twelve to fifteen months after the initial assessment, a final assessment is made. This is an opportunity to evaluate the support and services given to the patient from the pharmacy and gain patient insight into their views, achievement of health and wellbeing goals.



Pharmacy staff were asked to adopt a flexible approach to meet the needs of each individual patient. The exact number of interventions and contacts was not prescribed, however, a minimum requirement of at least 5 interactions over a year was stipulated. Each participating pharmacy was supplied with a resource box containing a number of different resources to support consultations,



including consent forms, a leaflet describing the role of community pharmacy and easy read leaflets (see Appendix 1- 3). Staff were encouraged to build and maintain a trusting and non-judgemental relationship with each patient and adapt a communication style and approach to suit each patient.

Every *Making Time* pharmacy is also part of the Safe Places scheme. Safe Places schemes help an adult with a learning disability cope with any

incident that takes place while they are out and about, for example being harassed, getting lost or the person they are meeting fails to turn up which causes them to need assistance.

For further details on the service please see service details at <u>http://www.cpwy.org</u>

#### Training

The first wave of pharmacies were invited to a multifaceted training event which introduced the service and allowed pharmacies to ask questions. This included:

- Information from the commissioner on the background to the project and why it is important
- A video produced by a drama group of people with learning disabilities showing a 'good' and 'bad' community pharmacy experience
- Support from care service providers on recruitment.
- Practical information on how the service works

The initial training was followed up with a workshop after six months of delivery. This was an opportunity for the first wave pharmacies to share ideas, experiences and challenges with each other and the *Making Time* board. Attendees also described how they could support each other and how the *Making Time* Board could support them. Information on communicating with patients with learning disabilities about health was also presented.

The training approach for the 2<sup>nd</sup> wave of pharmacies was rationalised to facilitate faster implementation and to address the whole team, responding to feedback from the first wave. These pharmacies were visited twice; firstly with *Making Time* resources at a time convenient to them where the project was explained; secondly for a follow up once staff had chance to read materials. A follow up workshop is planned for later in the year.

#### Development and Support for Making Time

The *Making Time* Board are responsible for guiding the development and delivery of the service. The Board is made up of a number of professionals who have a vast experience of working with people living with a learning disability. It consists of commissioners, service providers, a patient involvement

specialist who works with patients with learning disabilities, a CPWY representative, a GP and a communications lead. Service user opinion is fed in via a separate user group through the patient involvement specialist. The aim of the board is to monitor the delivery of *Making Time* and to support the development of the service.

Community Pharmacy West Yorkshire is funded to provide implementation and ongoing support and monitoring of *Making Time*. This includes:

- Producing the service guide
- Designing data capture forms on PharmOutcomes and regularly monitoring activity
- Organization of training events
- Attendance at the project board and provision of regular updates
- Visiting pharmacies to provide ongoing support in service delivery
- Service evaluation
- Co-design of patient materials (see appendices 1-3)
- Regular newsletters to participating pharmacies
- National promotion of service linking with NHS England and Public Health England

Figure 1 Summary of *Making Time* contacts

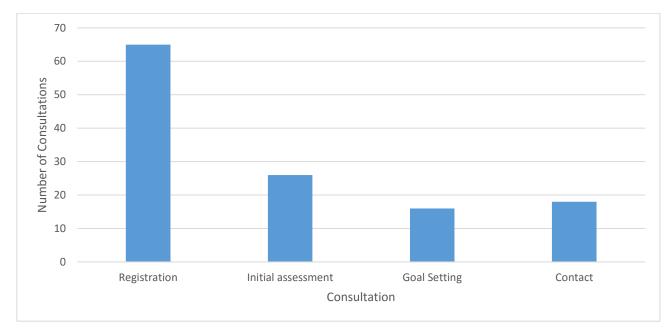


## 4 METHOD OF EVALUATION

All data inputted on to *PharmOutcomes* was evaluated from 10.9.2015 to 16.5.16 Data was extracted into Excel and reported using descriptive statistics. Goals and actions recorded in *PharmOutcomes* have been thematically analysed and reported. Several patients have also been individually tracked on *PharmOutcomes* using anonymous patient ID numbers to produce a narrative of their journey to date. Ad-hoc feedback from one pharmacist and one carer has also been reported.

## **5 RESULTS**

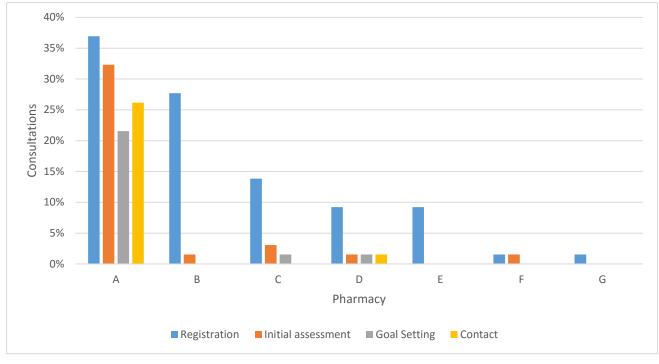
To date, 65 people have registered with the *Making Time* project; 27 (41.5%) female and 38 (58.5%) male. Twenty six of these patients went on to have an initial assessment, with 16 setting goals (see Figure 2).



#### Figure 2 Number of patient contacts at each stage of the service

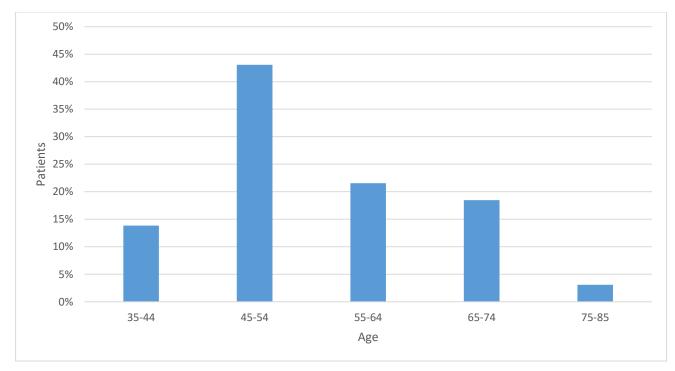
*NB* the number of contacts is greater than the number of goal setting consultations as patients only have one goal setting consultation but may have multiple subsequent contacts.

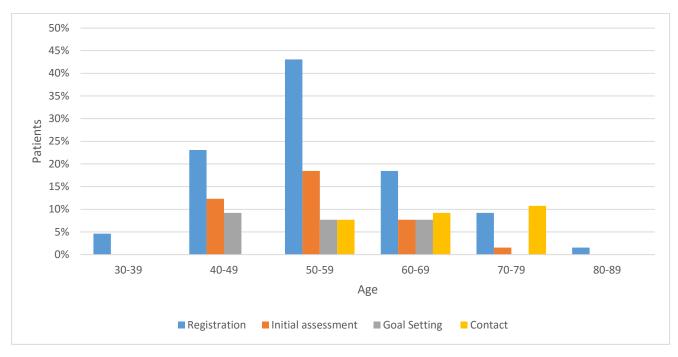
The majority of registration, assessments and follow up were undertaken by one community pharmacy provider (see figure 3). The age range of the patients registered ranged from 35 to 85 with most being between 45 and 54. The patients who went on to have most contacts were aged between 50 and 79 (figures 4 & 5).



#### Figure 3 Number of contacts at each stage of the service by pharmacy

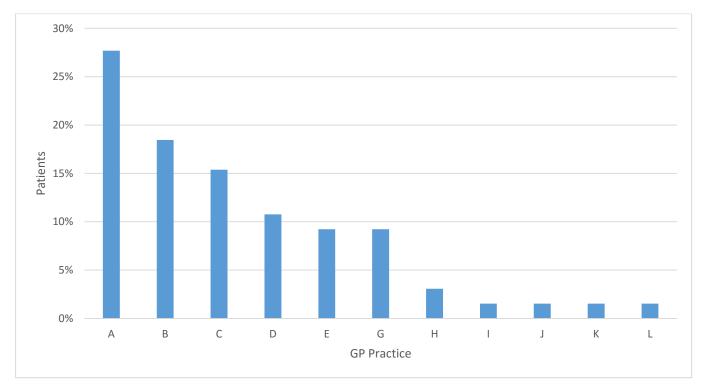
#### Figure 4 Age of patients registering with Making Time

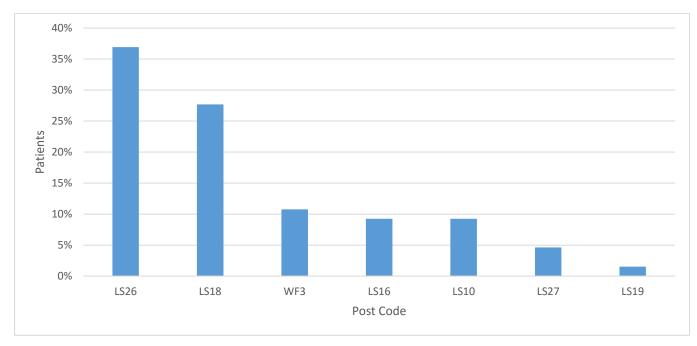




#### Figure 5 Age of patients attending each stage of the service

#### Figure 6 GP practice of patients registered with Making Time





#### Figure 7 Post code of patients registered with Making Time

Nearly three-quarters of patients were registered at 4 practices (47/65, 72%) (see figure 6). This may be reflective of the postcodes where the patients live (see figure 7). All patients using *Making Time* had a carer who supported them. The majority of these were paid carers (63/65%, 96.9%)(either personal or employed)<sup>1</sup>, the remainder were family members. Following registration three patients were not suitable to progress to the initial assessment. Two had moved house and one could not get to the pharmacy.

#### **Initial Assessment and Goal Setting**

It took two appointments for over 70% of patients to complete their initial assessment. The time taken to undertake the different types of consultations varied in length; the subsequent goal-setting and contacts being half to two-thirds of the initial assessment (see table 1).

#### **Personal Carer**

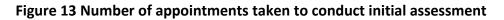
#### **Employed Carer**

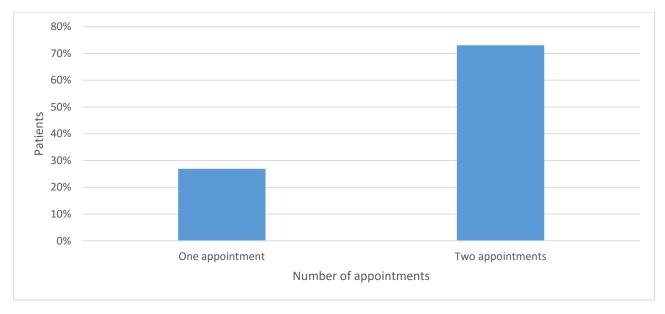
A paid support worker or PA (personal assistant) that is paid through direct payment or personal budget by the person living with a learning disability to support in all aspects of daily life

Employed by a social care organisation to support the person living with a learning disability in all aspects of daily life

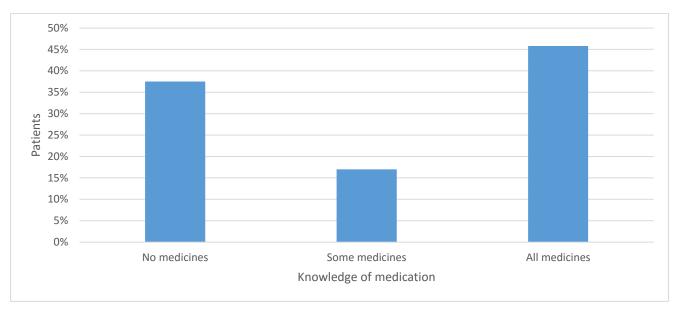
#### Table 1 Time taken for consultations

Time taken (minutes)	Initial Assessment (n=26)	Goal Setting (n=16)	Contact (n=18)
Minimum	10	5	5
Maximum	45	30	30
Mean	24.2	12.8	16.4
Median	25	12.5	14





Of the 26 patients who have had the initial assessment, 19 patients (73.1%) had a monitored dosage system (MDS), five had their medication labelled in normal packaging and two patients were not taking any medication. During the consultation, one patient admitted that they did not take all their medication (1/26) and half of the patients (15/26, 54.5%) did not know what some or all of their medicines were used for (see figure 8). These patients had their medication explained and two had actions for the GP as a result of the consultation.



#### Figure 8 Knowledge of what medication is used for by patient

A total of 36 goals were set for 16 patients (mean 2.3 goals per person) (see figure 14)

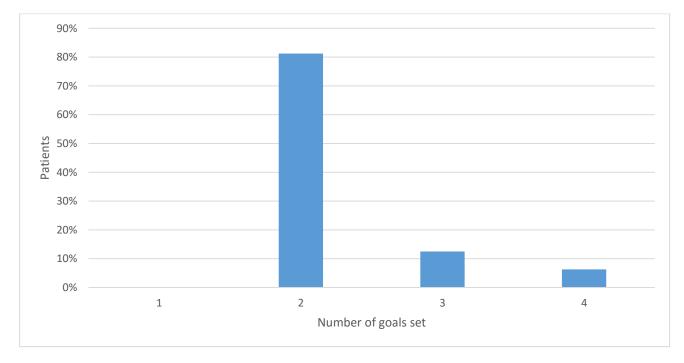
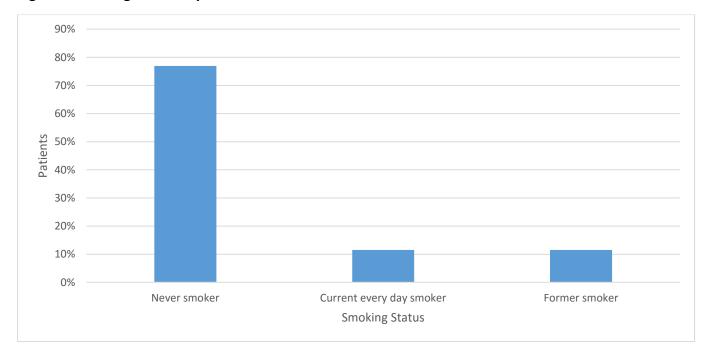


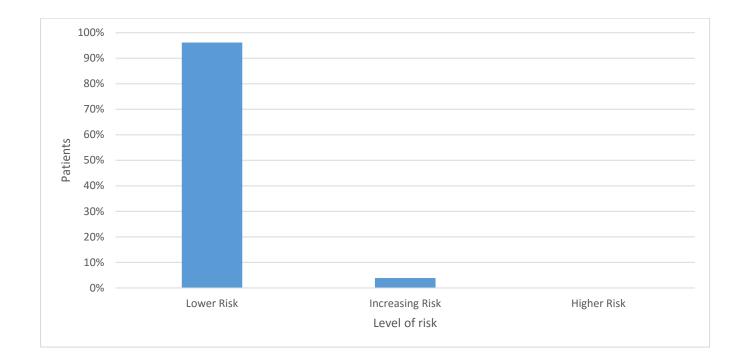
Figure 14 Number of goals set per person

Most patients had never smoked and their alcohol consumption was categorized as being low risk (see figures 9 and 10). There were three patients however who smoked daily and one had an increasing level of risk from their alcohol consumption. One of these patients set a goal to reduce their smoking and the other set a goal to think about stopping smoking. Only a quarter of patients reported that they undertook regular physical activity (using the GPPAQ assessment) with the majority being classed as overweight or obese (see figures 11 & 12). Nine patients went on to set goals about healthy eating with none setting goals around activity.

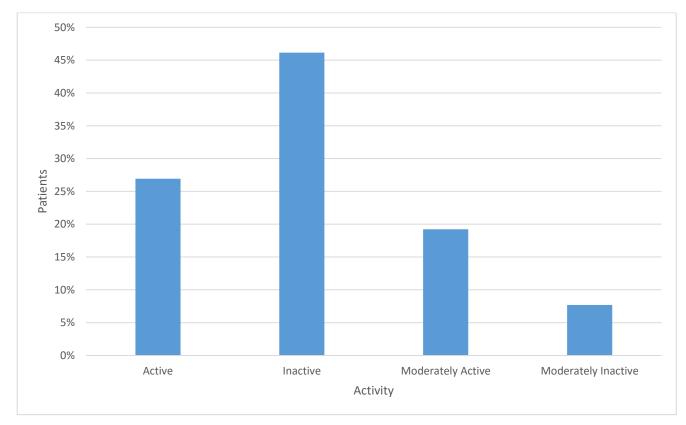


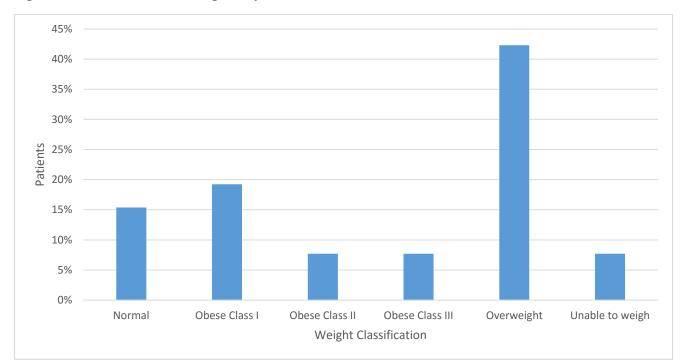
#### Figure 9 Smoking status of patients

#### Figure 10 level of Risk due to alcohol consumption

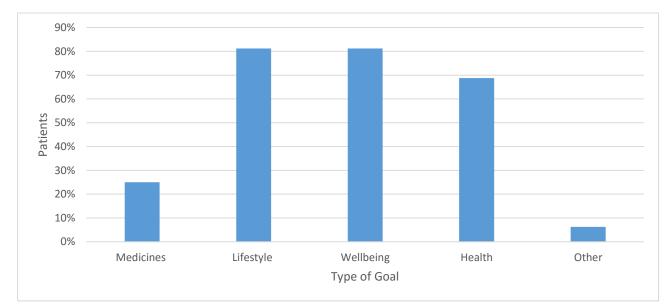


#### Figure 11 Level of physical activity of patient





#### Figure 12 Classification of weight of patient



#### Figure 15 Type of goal set

Discussions during goal setting and contacts ranged from basic, such as setting a goal to attend the next meeting in the pharmacy, to more complex such as learning more about their parkinson's medication and eating more healthily by understanding the content of different foods.

'[We] discussed healthy diet and portion sizes, which foods are healthy and not so healthy, which drinks are healthier with less sugar, less salt in diet. I gave her some leaflets to take away and refer to and agreed weighing again next week.'

Pharmacy Staff A

Discussions were tailored toward the individual, making helpful suggestions:

'[I] discussed diet - suggested wraps for lunch instead of Ryvita as [patient] bored of Ryvita. Discussed fruit and veg and 5 a day. Discussed getting a smaller walker so more mobile. [Patient] is going to Tiger Tiger social night once a month.'

Pharmacy Staff A

'[We] discussed diet and exercise and we are going to source an anatomy book that patient is keen to read'

Pharmacy Staff B

Patients were continually encouraged to work toward their goals even if not achieving:

'[The] patient had not reached weight loss goal but had attended each appointment. [I] gave another healthy eating leaflet (sugar swap) and re-explained the goal and general healthy eating advice. [I] arranged next Making Time appointment for one month but [patient] continues weekly weight checks'

Pharmacy Staff C

The pharmacy staff also provided reassurance and emotional support for patients:

'[The patient] brought in [her] script and was upset. [I] took her into consultation room to calm her down and talk to her. [She] was upset about a cyst on [her] finger and had been worrying it had been something that would need operating on and had been building up the anxiety for weeks. [She] saw the GP today and the upset was due to relief. I dispensed the prescription. [The] patient left happier and calmer.'

#### Pharmacy Staff B

Goals were often incremental, for example the first goal to think about stopping smoking before the next appointment where stopping smoking would be discussed or reducing smoking slowly before thinking about stopping.

'We discussed progress [with patient A] reducing her smoking from 60 cigarettes per week to 40. This has gone very well and we're now going to try to reduce to 30 a week over the next month. We also did an MUR and gave her some reminder charts to help with her medication.'

Pharmacy Staff D

Discussions were also held with patients when prescriptions were dispensed to advise them on the medication that they were about to take, recognizing the individual needs of patients.

'[The] carer doesn't feel any more planned appointments will be beneficial. Agreed to stop planned monthly appointments but continue contact as adhoc and on dispensing prescriptions.'

Pharmacy Staff B

Also on other minor ailments, such as travel sickness

'[We]Talked about travel sickness tablets for going on holiday. We agreed he will get a prescription from doctors and we'll sort it out.'

Pharmacy Staff A

#### **Patient Stories**

Using anonymous patient ID number several patients have been tracked on PharmOutcomes to produce a narrative on their journey to date (see table 2). These show a range of different goals set, tailored to the individual patient's needs, with various outcomes.

#### Table 2 Patient Journey

'PB is a 66 year old lady who doesn't take any medicines, has never smoked and is a low risk drinker. She weighs 116kg giving her a BMI of 50 and putting her in obese class III. She admitted to being inactive. PB has met with the Pharmacist on her own without her carer present on 5 occasions; two to undertake the initial assessments and the remainder to set and monitor goals. At the first goal setting meeting she set goals to come to regular appointments which she has achieved. She also set a goal to lose 1lb a week which she hasn't yet achieved but she continues to attend the pharmacy regularly to be weighed and for healthy eating and dietary advice.'

'PSS is a 64 year old man who takes 8 medicines regularly. At the initial assessment he only knew what one of the medications he was taking was for. His BMI was slightly on the low side and he admitted that he was inactive. With the support of his carer at the appointment he agreed to come to the next appointment and think about what goals he may like to set. He also discussed how he might gain weight and is using a healthy eating placemat to help him achieve his goal.'

'NC is a 48 year old lady who takes 2 medicines regularly, however at her initial assessment she only knew what one of her medicines was for. Her medication was explained and she set a goal to always discuss any new medication with the pharmacy staff when she brought in her prescription. The next time she brought in a prescription the pharmacy staff explained her new medication to both her and her carer.'

'AP is a 49 year old man who takes 2 medicines regularly but did not know what either of them were for at his initial assessment. He weighs 65Kg giving him a BMI of 27 and is moderately inactive. He set a goal around healthier eating and a further goal to attend the pharmacy regularly for appointments. Subsequently he has lost some weight through healthier eating and increasing his activity at day services. He is also undertaking cooking classes to help him with his healthier eating.'

#### **Testimonial from Pharmacist and Carer**

One pharmacist has provided a testimonial which describes their experience of, and approach to the service:

"We do dosette trays for a community home - supported living service which are flats for people with learning disabilities so the majority of our customers on the Making Time service are from this. We have also recruited a few customers who regularly use our shop for weight management advice who have learning disabilities.

The carers from the supported living engaged with the customers and asked them if they would like to take part in the Making Time service. The customers whom we recruited ourselves were very excited to be asked to join the service as they felt like they were being given a service specifically for them.

For each meeting we print out the relevant paperwork so that we can talk directly to the customers rather than flitting back to the computer to write notes. We printed out the initial assessment from PharmOutcomes and each audit (alcohol, physical assessment etc) and used this as the basis for the first appointment including weight, height, BMI. The second and third meeting was based around an MUR if appropriate. We asked Nigel for more leaflets on various medication that we could use to explain what each medication was for. Some of the patients are very well informed about their meds, others we spoke to the carer to get details.

We asked Nigel for more leaflets based around healthy living and diet and we will be using these for goal setting as the majority of our customers have a higher BMI than is ideal so we want to help them eat healthier or be more active.

The first meeting the customers were very nervous but since that first meeting they are much more comfortable with us and are happy to talk, even if they are just popping in for a prescription with their carer. I think they are benefitting from this service as it is giving them more confidence with discussing their medication and lifestyle. They are also more comfortable in the pharmacy environment and know there is nothing to be scared of. I also think it gives the pharmacist a better idea of what each individual can understand and their capabilities so i don't always talk directly to the carer when giving advice about prescriptions now.

Pharmacist X

Ad-hoc feedback has also been received from one patient's carer

"I thought you'd like to know that someone has just rung me to say how useful Making Time has been. They weighed and measured him, talked about diet and health. They even checked his medication. He's well chuffed and has appointment to go back to see how he is doing"

Carer A

## 6 **DISCUSSION**

The *Making Time* service is in its infancy and is continuing to develop and evolve. A high number of patients have registered with the scheme to date; a lower number have gone on to have an initial assessment and a goal setting consultation. The reasons for this are unclear and further work to explore this may help to understand how staff and patients can be encouraged to engage with the service. This will help to guide support given by CPWY. Where patients have set goals these were tailored towards the information gathered in their initial consultation.

It appears that it is the older patients who have returned to have further consultations within the pharmacy. This may be due to the patients having more experience in the healthcare setting, or the post-code of where they live in relation to the pharmacies who have delivered a higher number of

contacts or some other reason. It is unclear at this stage whether this is noteworthy as the numbers of participants are too small to draw any firm conclusions. This should be reviewed in the final evaluation.

The majority of consultations following registration came from a small number of pharmacies. Additional work to understand the reason for this and to share good practice should be undertaken. Currently the service relies predominantly on the recruitment of patients through the care network. GP practices have a responsibility to annually review the health of patients with Learning Disabilities. This creates the potential for patients to be referred to *Making Time* via this route. This could be explored further

#### Limitations

The small number of patients who have set goals and had follow up appointments makes it difficult to draw conclusions and assess generalisability of the current results, however it is clear from the patient stories and testimonials that for the patients who have used the service they have gained personal benefit.

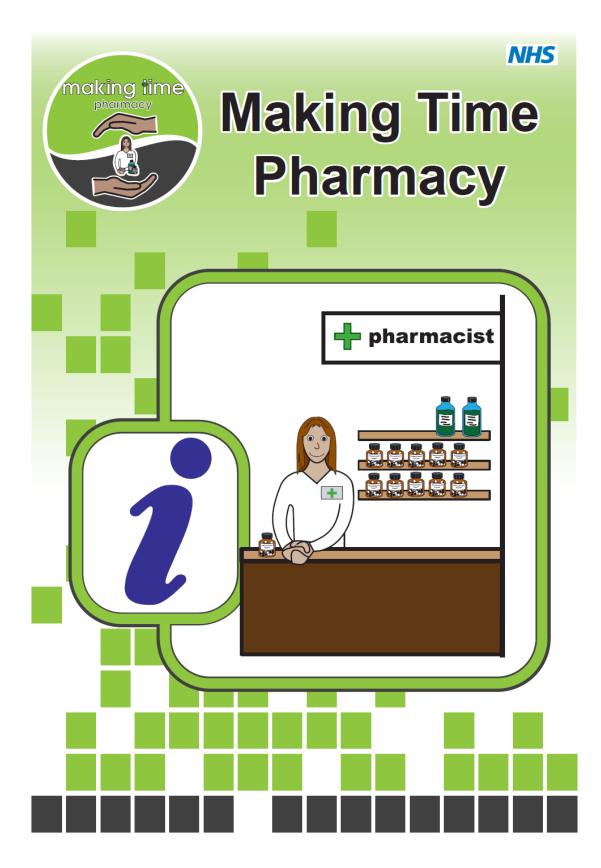
#### Recommendations

- Learn from pharmacies who are delivering high numbers of follow up consultations and share good practice
- Explore the reasons why the number of patients followed up from initial registration is low and determine ways to increase follow up consultations.
- Explore General Practice as a route of referral
- Increase number of goals around exercise to support inactivity and weight loss
- Explore self-referral form people living with a learning disability in the community (not statutory accommodation)
- Explore referral from family carers
- Routinely review the goals set by patients to determine what further leaflets may need developing.

## 7 **REFERENCES**

- Michael, J. Health Care for All. Independent inquiry into access to healthcare for people with learning disabilities. 2008. Accessed at <u>http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsan</u> <u>dstatistics/Publications/PublicationsPolicyAndGuidance/DH\_099255</u> on 14/6/2016.
- Heslop P, Blair P, Fleming P, Hoghton M, MarriottA, Russ, L. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). 2013. Accessed at <u>http://www.bristol.ac.uk/medialibrary/sites/cipold/migrated/documents/fullfinalreport.pdf</u> on 20/6/2016.

#### Appendix 1



## What is the Making Time pharmacy?



It is to help people with learning disabilities
get a better service from their pharmacy.



If you agree to take part in Making Time you will get



A Making time folder and membership card.



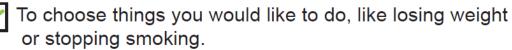
More time to talk to your pharmacist about the medicine you take.



Easy to understand information about your medicine and how to take it.



To find out what else your pharmacy can help you with.



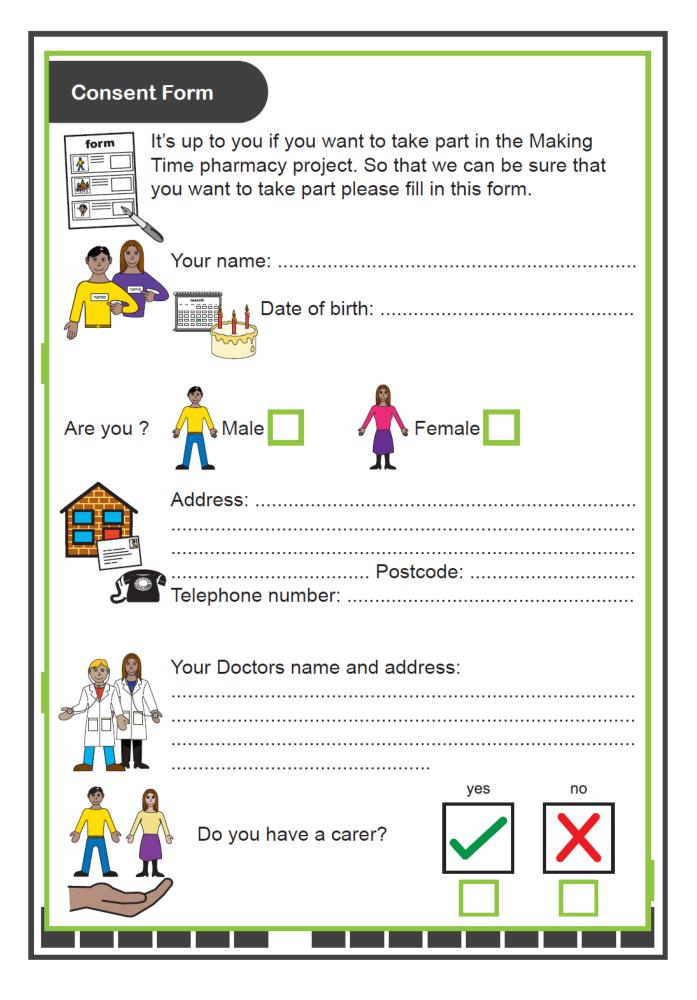


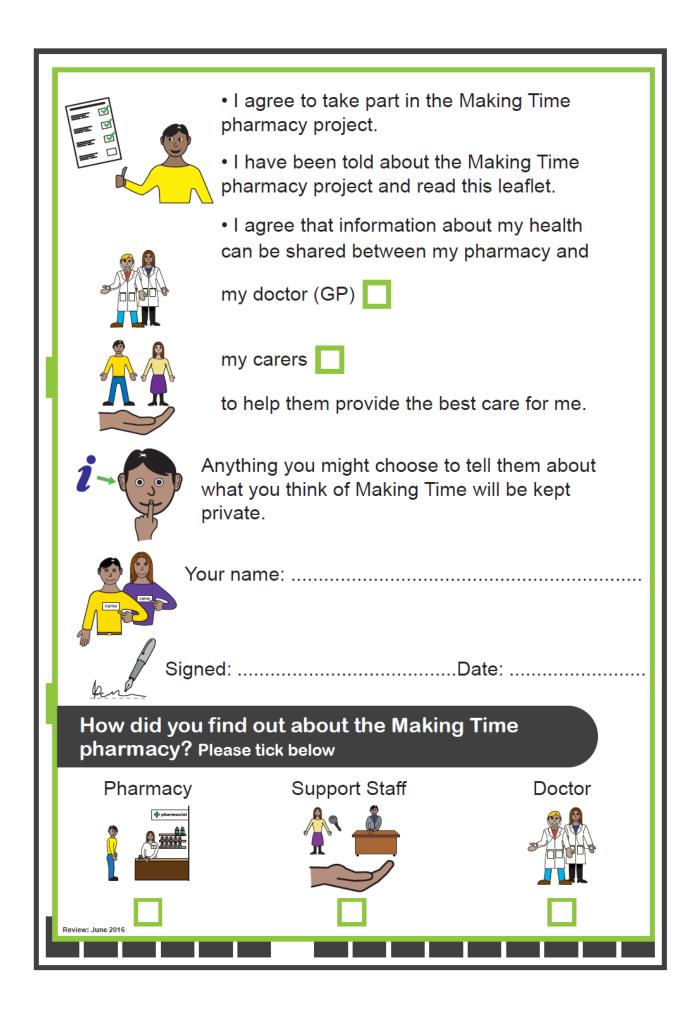
Special appointments for you to come back and find out more or check how you are doing.

## What should I do next?

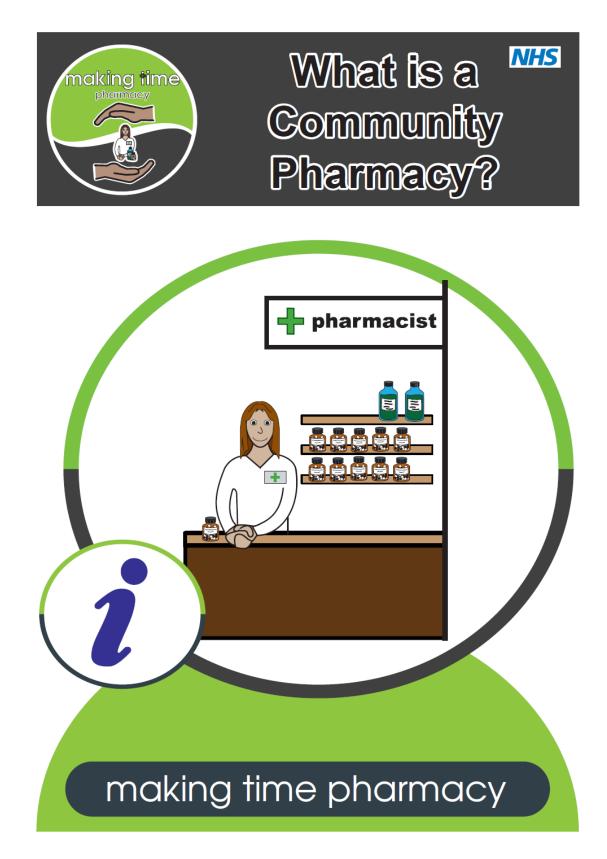


Just fill in the next section of this leaflet and take it along to your pharmacy.





#### Appendix 2



# What is a Community Pharmacy?



Community pharmacists were known in the past as chemists.

About 1.6 million people visit a pharmacy everyday.



Community pharmacies are in high street locations, in neighbourhood centres, even supermarkets.

Community pharmacies are all over the place!

Most people think of the community pharmacist as the person who you take your prescription from the doctor to.

But they do much more than that!

They can...

- Tell you how to be healthy.
- Tell you about other services that can help.
- Tell you how to look after yourself better.







# Why have I been given this medication?





Some medications are taken as a 'course of treatment' to cure a condition. Anticonvulsant medications are different.

You need to take them every day to try and stop seizures from happening.

There are different kinds of anticonvulsants for different types of epilepsy. You may need to take more than one anticonvulsant to stop your seizures.

# When do I take my medication?



medicine

Your doctor will tell you when to take your medication.

Different kinds of anticonvulsants are taken in different ways.

You should take your medication the way the doctor says. If you do not take them in the right way or they might not work very well.

You should not stop taking your medication without talking to your doctor. Suddenly stopping your medication might make seizures start again.

# When will I feel better?







It is hard to say how long it will take for your medication to work.

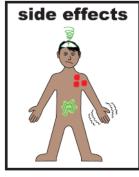
Some people's medication will start to work quickly.

For some people it may take a longer as they might need to try different medications.

The best way to see if your medication is working is to see if your seizures stop or if you are having less. You might want to keep a seizure diary to check this.

Sometimes a person with epilepsy who has had no seizures for 2 years could ask about stopping their medication. Your medication should only be stopped slowly over several months. You would need to talk to your Doctor about this.

# Will there be side effects?



Like all medication anticonvulsants can have side effects.

The side effects will be different depending on which anticonvulsant you take. Different people can have different side effects to the same medication.

medication list

Some people think the side effects are better than having seizures.

The side effects will be listed in the patient information leaflet that comes with the medication.

# Who do I speak to if I have problems?



If you have any problems with your medication you should tell your

Pharmacist • Doctor • Epilepsy specialist • Nurse • Carer







