Patient Experience Team

Continence Whole Systems Review

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Background and Introduction

Between January and May 2018, the Patient Experience Team has undertaken a whole systems review of Continence. The reason for focusing on this area was twofold. Firstly, much of the feedback gathered previously as part of monthly PE reporting identified issues relating to continence, including the impact that it could have on wellbeing if not addressed appropriately or effectively. The second reason was that it was clear that this is an issue that is a whole systems concern, as continence crosses primary and secondary care and involves social care too, so is a good place to test out a more focused and whole systems approach to the work undertaken by the Patient Experience team.

It was also agreed that in addition to talking to service users and carers it was equally important to talk to staff and stakeholders across THT to find out what works well, reasons for why it is effective, what doesn't work so well, and identification of potential opportunities for improving the pathway.

214 service users and carers shared their views. Of these 10 took part in face to face 1:1 interviews, and 48 participated in telephone interviews. The remaining 156 contributed through discussion in the following local groups:

Alzheimer's Carer Support Group (44), The Geezers (51), Arthritis and MS Support Groups (9 and 10), Osmani Parent's Group (12), St. Hilda's User Group (13), and TH Carer's Forum (15) ELFT Working Together Group (2).

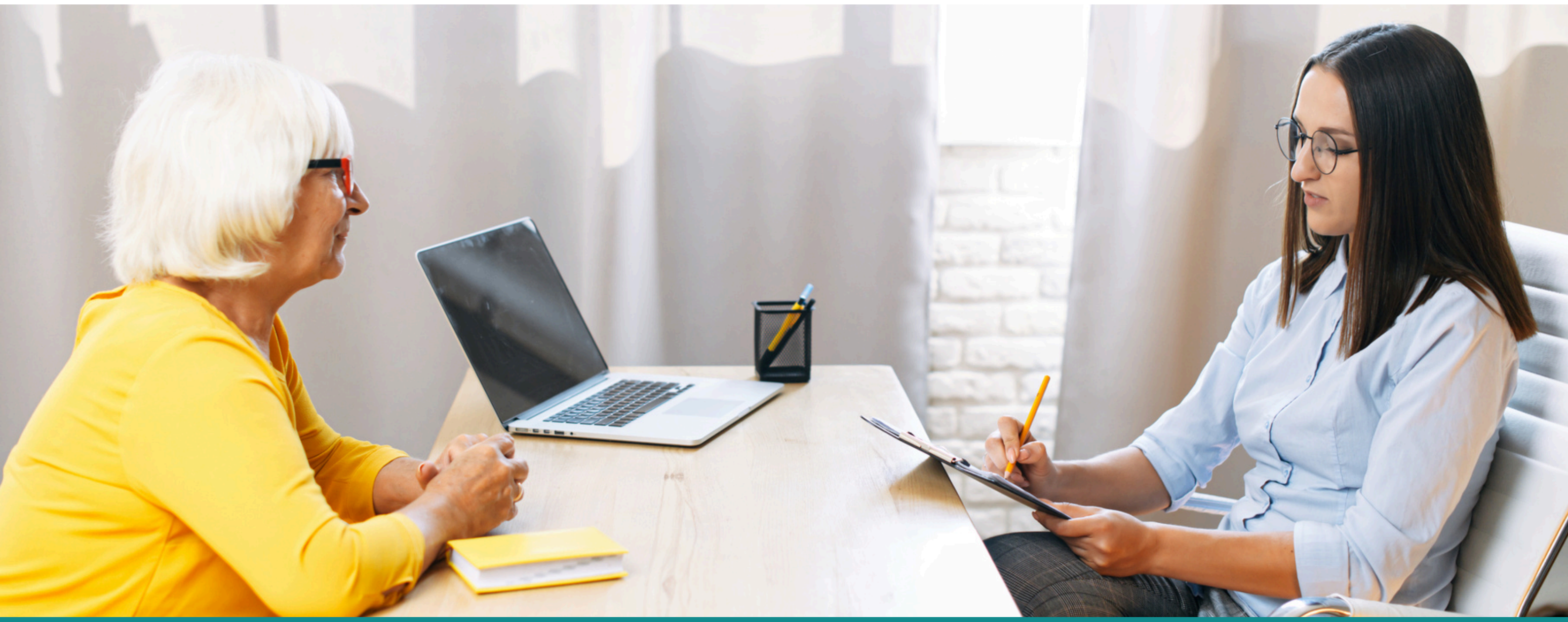
Executive summary

Individuals who shared their views were in receipt of support from the following Community Services:

NE EPCT (12), NW EPCT (6) SE EPCT (4) SW EPCT (10), Specialist Neuro Team (9), AADS and Rapid Response (5) and Falls prevention (Safe & Steady) (2).

In the course of the review, the following service providers and clinicians took part in 1:1 interviews: Specialist Continence Nurse Manager, Practice Nurse, Specialist Neuro Lead Nurse, RLH and Barts Hospital Specialist Continence Link Nurse, ELFT Therapies Lead, Specialist Neuro Team and Manager, Maternity Mates Manager, ELFT Continence Champions Group Lead Nurse, LA Reablement Community Nurse, Community Midwife Team Lead, Diabetes Lead nurse and Community Psychology Team Lead.

In addition to these 1:1 interviews, two Process Mapping sessions were held. The first of these was held at an early stage of the review and enabled an overview of current state and processes, and the second follow up held later and focusing on the learning and potential future state, which helped consolidate the above recommendations. Both sessions included the Manager of the Specialist Continence Nursing Team (ELFT), Social Workers x 2 (LA), Local Voluntary Sector Service Provider (Vol Org), SE EPCT Locality Lead Nurse, and AADS Team Manager (both ELFT).



Key recommendations

Recommendation 1: Assessment

Through incorporating continence into the assessments carried out by social workers, practice nurses, and other health professionals, the taboo around talking about continence is broken down and access to diagnosis, support, resolution or treatment are delivered in a more timely way. This can be done through adopting more user friendly language.

Recommendation 2: Assessment before provision of aids

That across the health and social care community, there is a consistent message about the need for assessment, and that continence aids and products are viewed as a “last resort”.

Recommendation 3: Flow charts

There is a clear flow chart available to staff and patients regarding how to access help and, where necessary, clear information about why they have been prescribed a particular product, activation and delivery arrangements for continence aids and products.

Recommendation 4: Integrated approach to training

That the LA delivers additional training in Continence awareness and management to social care staff to ensure they are able to assist service users to maintain healthy skin, to adhere to the prescribed continence aids, and where possible promote and support bowel and bladder care through encouraging a routine to enable people to remain self-managing wherever possible. Also incorporate Continence Training and awareness into GP training programme.

Recommendation 5: Pre discharge assessment

That Barts Health adheres to SAFER discharge bundle and best practice discharge procedures to ensure that all in-patients are assessed regarding continence needs before using any continence aids or products on the wards. Referrals should be made to SCN in a timely way to ensure that needs relating to continence are addressed prior to discharge, and orders submitted for any aids or products required in the management of continence.

Key recommendations

Recommendation 6: Integrated approach to awareness raising

That THT alliance partners adopt a common language for communicating what Continence is; helping to raise awareness, promote prevention and de-stigmatise continence management. That the THT also develops an Alliance wide forum and / or contributes to the Continence Champions Group to share information on ongoing projects such as prostate cancer awareness raising or PFE training in a community setting, as well as a flow chart showing available services to help manage continence, and explore opportunities for partnership working between the third sector and statutory services, such as Maternity mates.

Recommendation 7: Promotion of signposting to emotional support

Signpost service users to psychological support available, patient led support groups and support the development of new forms of support in response to identified need e.g. befriending and buddying peer groups.

Recommendation 8: Expand membership of Continence Champions group

Encourage alliance partners to join the ELFT facilitated Continence Champions Group for Continence to both raise awareness of prevention strategies and ensure cross organisational awareness of best practice re continence management. In addition to this, THT Alliance partners seek to improve engagement with service users by working with and supporting the Third Sector to help promote healthy bowels and bladders through education and training in PFE's etc. to promote preventative strategies.

Recommendation 9: Resources to support prevention and management

That the CCG explores the possibility of performing a social prescribing or commissioning function in relation to continence management or prevention of problems: releasing Health Budgets to enable people to access appropriate community support/activities such as PFE's, N-Able or overnight toileting to prevent continence issues resulting from mobility problems.

Recommendation 10: Incorporate into PHSE syllabus at school

That consideration is given to encouraging incorporation of Continence awareness and PFE skills to the education syllabus under PHSE.

Recommendation 11: An integrated approach to piloting new initiatives

Key messages and themes from the work

Need for more preventative approach:

General consensus amongst clinicians, health and social care agencies and individual members of the community was that an early approach to awareness raising amongst young people would be hugely beneficial. School nurses may be in a key position explore the potential to include information about benefits of Pelvic Floor Exercises (PFE's) as part of as part of personal, social, health and economic education (PSHE). As a Community midwife shared:

> "…. yes, awareness needs to happen earlier, because I have a pregnant 16 year old who is in Year 11 and no-one has spoken to her about bladder care… because I'm a midwife, I talk to her about everything, but she has not come back, and even though they've had a lot of sexual health teaching and information at school, bladder care was not part of it, or doing pelvic floor exercises, or its benefits, that wasn't discussed at all."

Sensitivity among people of faith is also a potential challenge to young people being able to access information about PFEs:

> "…parents are given the option to pull their child out of PHSE classes, so what you find is a lot of parents who are maybe of Muslim background or Catholic or whatever, may pull their kids out of it. So some girls don't attend these sessions anyway…"

It may be that by reframing the discussion to focus on general health and wellbeing rather than associations of sexual or reproductive health it may be possible to engage with parents who may be concerned about PHSE classes, and also tap into evident enthusiasm and interest in having a fit and healthy body that is prevalent among many younger people.

Key messages and themes from the work

Midwifery and Maternity Mates:

At ante-natal classes and appointments with midwives there is a pro-active approach to raising awareness of the importance of PFEs, but these target first time mothers, and it is clear that many women do not attend ante natal classes, or maybe only attend the first one.

> "...in terms of parent education classes, we do target first time mothers. A lot of the mothers who may come as asylum seekers or so forth are not first time mothers, and a lot of them also don't speak English. We do have a Bengali class that we run with the health advocates, because in terms of ethnic minority, the Bangladeshi community is our largest. Given available resources, we've put on sessions for them... but unfortunately in terms of uptake, it's not very good.... I think in terms of how their family structure works and coming out to the classes, it's that... a lot of the times, the sessions are maybe two or three sessions, so they may come to the first one and they don't come to the others."

Reasons for not attending all the sessions are many and varied, but may include cultural issues, whereby there is a reluctance to over-medicalise pregnancy and childbirth, with a preference to gain knowledge and support from family and peers rather than the healthcare system.

> ".....in the Somalian community, they may say, 'We've had so many babies, why do you need somebody to tell you how to manage your bladder? Why do you need somebody to tell you how to eat properly, to tell you how to have a healthy diet, or to make sure you have your checks?'.... because they see pregnancy as a natural process and they feel having all these things told to you changes the whole experience. We've had this with iron tablets; the perception was if you have iron tablets, you'll have a big baby. They would say, "Don't give it to me, my baby will be too big and I need a small baby to make labour easier." You find older mums will do it but not the younger ones, and in terms of bladder care, continence issues as well, it's the same."

Key messages and themes from the work

New approaches are being piloted by Community Midwifery in an effort to counter some of these challenges. A group which includes a mix of first time mothers as well as those who have already had children are given the opportunity to support each other. This is a place where discussions about continence can take place in a safe environment and where some myths can be debunked:

> “We started this new thing called the Pregnancy Circle and it’s really good; it’s a different type of antenatal pregnancy journey, where you have a group of 8-12 women and they discuss pregnancy. So topics are put on the table and those who have information or feel they know about it will talk in terms of what knowledge they have. The midwives will add to it, but the group is teaching each other, so it can be a combination of 1st time mums, 2nd time mums, so they’re learning from each other. One may say, “Oh, I had this rash!” or “I’ve got swollen legs.” And then one of the mums will say, “Oh, I had that, this is what I’ve done and it helped. The midwife says, “OK, what we recommend, as clinicians is …” But it’s good because what you find sometimes is the patients will take their peers’ advice more … which is what they do anyway in the community over the clinician. They prefer the women, their peers, to interpret for them as well. And it worked brilliantly; we did about five groups as pilots. They want to do a randomised trial of that, starting in June/July, so they’re going to start recruitment. And it’s different social classes, socioeconomic groups so it’s a mixture; you had the professional mums, the stay at home mums, the Bengali ones who couldn’t speak much English and they all just bonded as a group.”

This approach is seen as more effective and powerful than giving out leaflets, as the feedback from new mothers/parents was that they suffered from information overload and any advice sheet on continence and PFE’s would likely be discarded:

> “At booking, we give them so much and the community midwifes will say to them at the end, “Oh, you remember those leaflets you were given at booking?” and most of them have chucked it all away by the end of the pregnancy. The postnatal ward tried group discharge discussions, going through all the information in the pack, explaining to mums what to expect when they go home, just giving them health promotion and general advice. But there was reluctance; they don’t want to get off the bed, so it wasn’t well attended.”

Key messages and themes from the work

Another initiative that it is hoped will improve awareness of PFEs and continence issues is the introduction of a Home Birth Scheme whereby the same midwife builds a relationship throughout the pregnancy and birth:

> "... we've just recently recruited for a home birth team, so now these women are having one to one care and will meet that midwife for their first appointment and they will see them until birth. And especially for those who choose to have a home birth, those midwives will keep going back to them at home and I think in terms of education and opening up to your midwife that will improve the scope for prevention of continence problems."

TMothers identified as in need of additional support are able to gain support from Maternity Mates.

This service is delivered by a local Tower Hamlets Voluntary Sector organisation and aims to provide a volunteer 'doula' to support women throughout their pregnancy and for 6 - 12 weeks after the birth of the baby or longer as appropriate. Local women are recruited as volunteers and given comprehensive training (Level 3 accredited Doula skills and breastfeeding support skills), which often leads to qualifications in nursing or midwifery in later years.

> "We follow the NICE criteria: someone who meets one of the complex social factors, we take them on. So, say, for example, a first time mum who has no family and friends, a mum who had domestic violence experience before, a mum who had a traumatic birth experience, a mum who has mental health issues, a mum who is new to this country and has no social network, or a mum who has other issues, like obesity or gestational diabetes. The training for volunteers is delivered by two midwives employed by us. One is a sessional midwife from the City University and one is permanent four days a week with us."

AThe volunteers work hard to provide additional support to women to access information and accompany them to antenatal classes, where continence advice will be available:

Key messages and themes from the work

"Our Maternity Mates role is to introduce, year are encouraged to attend classes, write birth plans, and discuss pain relief options and birth choices. During labour, Maternity Mates provide emotional and practical support to ease the mums birth experience and continue postnatally, breastfeeding and signposting them to appropriate agencies. Queen Mary University Women's Health Research Unit is working with us to help us to do the clinical evaluation. We have a database worker who has access to records for the three sites of the hospital. This way we can see how many mums had a normal birth, how many had a planned C-section or elective C-section, how many mums initiated to breastfeed, how many mums continued to breastfeed, all that info they use, and the intervention, and the low birth weight baby, bladder health and all of this stuff, we record all that and we compare with our local targets."

There is also evidence that this model is sustainable as the flow of volunteers is replenished through the mothers themselves training as doulas:

"We've had mums who have become volunteers, because when they were in their first pregnancy, they didn't have any support at all, so therefore they had all those complications. But the second pregnancy, they were with the Maternity Mates, so they wanted to give something back to us."

There is clear evidence that Community Midwives are also making concerted efforts to focus on and explain the importance of bladder care throughout pregnancy:

"I managed the Community Birth Centres, so in terms of the Community Midwives, it's something that they definitely discuss with the woman, throughout the pregnancy....the expectation is when they see the woman, they'll talk to them about pelvic floor exercises, the importance of it, in terms of their bladder care, in terms of improving their own pelvic floor as well as for birth and about the damage that can potentially be caused from the birth ....It's discussed with the mothers again postnatally when they visit them at home, encouraging them to do PFE's, especially when they've had a lot of perianal trauma in terms of their bladder care, and in terms of making sure they're emptying their bladder.... that information is given to the mothers antenatally and postnatally.."

Key messages and themes from the work

While there are existing checks and balances in place to try to ensure that any issues or problems are picked up in a timely way following pregnancy and childbirth, not all women will take advantage of what is offered:

> "First you have the midwives, the wards, unless anything was highlighted during the birth ... because if she had a normal birth, she'd probably be in the hospital for 24-48 hours. At home the Community midwife sees you for the first 10-14 days; if nothing is highlighted during that period of time, then it's the Health Visitor and they see you initially for a couple of visits and then it's just popping in primarily for the checks on the baby."

GPs are responsible for carrying out six week checks post-delivery, and this too offers an opportunity to raise any concerns about Continence, although it is recognised that not all women may feel comfortable with discussing the issue. However, if this is refused it will be recorded as 'patient declined examination'.

Reasons for declining this can be many and varied, including availability of a female GP (although unlikely, as most GP Practices in Tower Hamlets have at least one female GP), a lack of rapport with the GP, regardless of gender, or a lack of awareness that the problem may be reversible, and an assumption or acceptance of the issue as simply a by-product of pregnancy and childbirth.

> "In terms of postnatal appointments, the six weeks appointment will routinely be booked with a female GP; they may have to wait up to seven weeks but they will get them to see a female GP. I suppose with everything it's a cultural thing, because if a woman doesn't feel confident about talking about continence, they won't, because there are things that some women would just not talk to anyone about, so there's always that barrier."

Key messages and themes from the work

The Head of Community Psychology suggested that training for GPs could offer them greater insight into the impact of continence issues:

> "For GPs and Practice Nurses, they have afternoons at the Education Centre at Mile End, and usually there are about 100 people, so wouldn't it be great if we could get continence down as a topic for one of those? If one or two of the people who told you their stories were to feel comfortable enough to do a synopsis of the impact on their lives or maybe film them and just show a video of them being interviewed it would bring their direct experience to the GPs."

Challenging the taboo:

There was recognition that men and women can be in denial about having a problem and find it hard to discuss continence issues in a timely way. The Geezers are a group of local mainly white working class men who meet to share interests and combat isolation. They also provide a very positive model of good practice as 'Health Champions', achieving excellent outcomes around raising awareness of and recognising symptoms of prostate cancer, so they may be a potential vehicle for raising awareness of the benefits of pelvic floor exercises.

There is of course a need to tap into forums attended by other culturally specific groups as a way of promoting discussion and awareness of prevention. Throughout their work the PE Team have been forging links with local community in the belief that trust can be established through proactively visiting the groups rather than expecting people to attend meetings hosted by the team.

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Accessing help

GPs can be the first point of contact but time pressures may contribute to reinforcement of messages around pads being the likely management option rather than having the time to explore the issue in more depth or seeing pads as last resort. The lead Specialist Continence Nurse (SCN) has been in touch with Tower Hamlets Community Education Provider Network (CEPN) to offer a regular slot in Continence Awareness at GP training programmes.

In patient issues

Feedback from service users, carers and staff highlighted challenges around continence problems arising while people are in-patients and the impact of this post discharge. This is thought to be due to a number of issues, including challenges around staffing, which mean sometimes people are given pads to maintain dignity rather than risk accidents, particularly if there is a need for two people to assist a person with mobility issues to the toilet. This use of pads can create risk-aversion and lead to ongoing and inappropriate reliance on pads. SCN's assert that pads should be viewed as a 'last resort' rather than given out as a safety measure.

Similarly, if staff do not refer to the SCN at the RLH and Barts in a timely way, people may be discharged without an assessment, and have a delay in accessing appropriate diagnosis, support, management or treatment for their continence issue. Community staff are well aware of the pressures on beds:

> "The pressure on the beds at The London, it's like, "What are you waiting for with this patient?" "Oh, we've sent off the continence referral, so we just want to check the DNs have got it." "Right, send them out!" regardless of whether the DNs have got the referral or not or whether everything is in place."

Allied to this, Community Staff who have tried to raise concerns about people being discharged without assessment have found that if they are employed by one of the Alliance partners other than Barts Health, the Datex systems do not 'communicate' with each other. They are therefore often uncertain as to how to ensure their concerns have been logged and acted on and learning shared, so clarity around the Pathway that enables cross organisational reporting and learning would be useful. Similarly, where nurses in an in-patient environment may be under severe pressure, this can lead inadvertently to an assumption that pads or continence aids may offer the simplest and most dignified solution. If someone requires two people to assist them to the toilet, where staffing pressures may lead to an accident, ward staff seek to maintain dignity, so will see provision of a pad as a timely solution.

In patient issues

It was felt by Community Nurses that this initial step is likely to have very significant repercussions once the person leaves the ward, as they lose confidence in their ability to regain independence. This provision of pads in hospital to a person who has been previously able to manage their continence is seen as contributing to a process of disempowerment and erosion of confidence in patients who begin to doubt that they can regain control and independence. While Community nurses too face significant pressures, there was a shared view that it is therefore very important that a consistent message about the need for assessment and understanding of the cause of incontinence is put across. As one nurse put it:

> "Because people are living longer, it's good that they are taught how to manage their condition and to own it. They know what is going on and they know how to manage it, and I think that empowerment should be passed across to people, rather than taking away their independence. You know, as soon as you are diagnosed with continence issues, we take it from there and somebody else manages it.... so if you have the hospital and GP's saying 'you'll get pads', it's counter intuitive. The most effective way is if people hear the same thing throughout their journey..... and if they hear it from the start.... and right through, it becomes the culture within the service".

Some people do self-manage continence issues through purchasing products themselves, but through doing so may not access appropriate help to reverse a problem or receive a timely diagnosis and treatment. For example, options around bladder training or spasms which can be treated through medication would not be appropriately explored.

Timely assessment of any problems was identified across health and social care as key to preventing avoidable long term use of pads. For this reason, there was universal agreement that having a central store of pads for emergency use, such as when a person was awaiting assessment, or if assessment did not take place as it should have in a hospital environment, was not a positive solution.

In patient issues

Although family members find delays in accessing pads frustrating, as well as suffering financial hardship incurred through the expectation that they will buy in supplies in the interim, it was strongly expressed that a store would not offer a solution.

"...rather than having a store where people can take pads in an emergency, because anybody can go and say, oh, that pad would suit Mr X or Mrs Y, and give it to them, but there are assessments that need to take place, and if we can assess you as an individual we can also work with you in getting that confidence back. If the confidence doesn't come back, we can look at, OK, what's your fluid intake, how much do you drink, when do you drink? Do you leave it until 6pm to have gallons of water? So if you wait until the evening to have lots of water, what you then expect is that overnight your bladder is full, you lie down and your whole body relaxes, including the bladder and you need to run to the toilet. So it's looking at strategies to manage it..."

Patient repercussions of cancellation of POCs

Local Authority colleagues shared concerns around the number of care packages that have been reduced or cancelled following the introduction of charging for services for eligible people. One of the issues highlighted was the impact of cancelling care that previously assisted an individual to use a toilet or commode, and who instead decided to make other arrangements. Robust review systems have been implemented to ensure that alternative and workable plans are in place should cancellation be requested and safeguarding procedures used where appropriate.

Where the alternative arrangement relies upon family members, Social Workers are careful to counsel people about the long term commitment and potential strain of taking this on, and recognise the potential impact on familial relationships. Potential Safeguarding concerns were also raised as an issue, as it was feared that it was not always clear initially whether the service user was cancelling the package, nor whether they fully understand the potential longer term implications of cancellation of the package. The concerns are around whether at best, it may be the ‘rainy day’ syndrome, where people become anxious and fearful if their savings dip to below a certain level, or at worst whether family members may be encouraging or coercing the cancellation of a POC to protect their own financial interests.

However, it is important to recognise the sense of injustice that the introduction of the charging policy has evoked, even though other boroughs have introduced such charges many years prior. Interviews with service users and carers do reinforce the sense of unfairness felt by those who have saved all their lives and now feel penalised through being expected to contribute to their care costs, while it is perceived that those who spent all their money are not having to contribute to the cost of their support. While it is an issue that has clearly caused both resentment and tension, the potential impact on the NHS is substantial.

Data analysis

As part of this whole systems review, attempts have been made to access pre and post charging data to analyse whether there has been evidence of a spike in requests for Continence assessments by Community Nurses, and any parallel decrease in requests for commodes, hoists or packages of care to support continence management, however this data has not been readily available. In the case of community nursing, post transfer of the service to ELFT there is data available, but prior to that the data does not seem to be accessible, so may be the result of changes to recording systems that accompanied transfer of the service.

Pro-active approaches to managing continence:
ELFT Community Health Services have set up a number of champion groups, and one of these is specifically around continence and led by the Specialist Continence Nurse Manager. The driver for this was a number of Serious Incidents (SI's) concerning catheters, two of which resulted in hospital admissions and the other in an admission to ITU. The need to tackle catheter care was therefore seen as a priority. Most of the issues were identified as being linked to the frequency of the catheter change and scheduled changes being missed. Where a patient is 'self-caring' in relation to their own catheter care, it became clear that a mechanism to trigger regular follow-up visits to monitor and review the self-management would also help prevent SIs.

The creation of the Rapid Response and Intermediate Care Teams also enabled identification of the high numbers of catheter related referrals, and this led to an acknowledgement of the need to treat catheter care issues as being potentially equally serious as insulin management or leg ulcer prevention in terms of the potential impact on a patient.

Data analysis

The way the Champions Group went about addressing this initially was to get each of the localities and night service to log the number of patients with a catheter, to enter data into a spreadsheet by patient, log the catheter size, the date it was due to be changed, whether the patient is having the catheter flushed, and any other relevant information. It then became evident that an average of 15-20 people within each locality have a catheter in situ, whether Urethral or Suprapubic, and this data had not previously been available at a glance.

At the same time, Rapid Response, Intermediate Care and the night service kept a spreadsheet of how many calls were received relating to catheters, and the nature of the problem e.g. blocked, leaking or bypassing catheters. The Continence Champions and lead looked at these sets of spreadsheets and were quickly able to Identify a number of people reporting problems with their catheters who were not previously known to their locality teams, as they had been discharged as in-patients without a referral for further care being made to localities. Rapid Response or the night team would pick these patients up and would find no supplies in the home, and so identify that District Nurses were unaware of these patients' needs. This is now being addressed through Datex reporting and awareness raising by the SCN attached to the RLH as mentioned in the In-patient issues section.

This work has already seen some positive impacts and has resulted in improved planning and scheduling of re-catheterisation, awareness raising of any problems such as blockages or crusting that may require a more proactive approach and change dates to be brought forward.

In addition, patterns were identified by Rapid Response and Intermediate Care around patients reporting blood in their urine following catheterisation, so a strategy was devised and implemented by the Champion Lead to give clear communication to patients regarding some of the potential side effects.

Data analysis

Thus a consent form that patients sign which also contains information about potential issues following catheterisation has acted as an effective way of reassuring patients and alleviating anxiety, as well as leading to a reduction in avoidable home visits being made by Rapid Response. There is evidence that patients are now more likely to seek telephone support and advice prior to a visit being made. In addition to minimising avoidable home visits, the system also has added benefits from a documentation point of view, providing nurses with evidence that consent was gained and potential side effects explained.

Another pro-active initiative is being implemented through Rapid Response (RR) use of a bladder scanner. Providing the GP is happy for catheter removal to take place (following surgery for example), the RR team can undertake this, give advice and then follow up to monitor wellbeing. A RR nurse reported:

> “We will say ‘You need to drink plenty', then you give them a ring to see if they’ve passed urine; if they have then we’ll go round, ask them to pass urine again and then scan to make sure that they are emptying their bladder out. And it means that they don’t have to go to the TWOC Clinic at the Royal London”.

Yet another initiative that has been pioneered by the Continence Champions Group is the creation of a check list for catheterisation:

> … we’ve developed a check list and it makes life a lot easier, because the check list is around, have you labelled the bag, have you done the stat. log, are you competent to do the catheterisation, and what size did you put in, was there encrustation around the tip of the catheter…?

Data analysis

Product developments (such as Farco-Fill) have also reduced the numbers of UTIs ,as described by a nurse:

> “.... there’s a product which has got tryptophan in it and over the course of four weeks, the tryptophan moves from inside the bladder to the outside, and it puts a film over the catheter, and the bacteria that was causing problems isn’t then able to adhere to the patient. So if the catheter can stay in for 12 weeks, you need to put in the product every four weeks, and this has reduced the UTIs and the blockages that were going on as well.”

Causes of continence issues

In terms of understanding the various causes of incontinence, this is agreed as being key to providing effective support. As one of the ELFT Continence Champions stated:

> "Part of the continence assessment is actually looking at why the person has been incontinent anyway ... some of it may be because they can't get to the toilet, some of it may be functional, some of it could be dexterity because they can't pull their pants down and some of it may be anatomical ...if they've got prolapsed uteruses or pelvic floor issues ...".

Another issue could be around cognition, where an individual forgets to go to the toilet or becomes disorientated around where it is. One of the latest innovations for helping with this is use of technological aids such as Memorabell through the introduction of a toileting routine using the recorded voice of a familiar and trusted family member. As one LA colleague explained:

> "... at 12 o'clock, you record "Mum, don't forget to go to the bathroom!" and things like that. If a person is confused, a disembodied voice could actually be very confusing so what they tend to do is have it set up with the family and the client there, and the daughter will be saying, "Mum, I'm recording this. So every time you hear that it will be like, (daughter) is reminding me to go the bathroom."

Occasionally the causes of continence issues take some time to establish, as illustrated by the following quotes from two patients:

> "...I sometimes dribble or take half an hour in the toilet just to clear it out of my system. At times I can't hold it in and I soil myself all over the kitchen floor. I spoke to my G.P about it initially and the nurses have done all sorts of urine tests and blood tests and couldn't find the cause."

> "....I've still got a urine infection and am on antibiotics. I've not had anyone plan anything around my care apart from they provided me with pads; I'm still on pads. My doctor's requested I see a consultant at the Urology department to get my bladder checked in August but it's now been changed to November and I'm struggling both with my bowel and urine. The delay has now become the issue for me as my urine doesn't clear out properly; there's always still some left behind which then becomes infected and they don't know why... "

Causes of continence issues

The proactive approach adopted by Continence Specialist Nurses and Champions sums up the need for a thorough assessment and early identification of causes:

> “So what we’re going to move towards is to get post op catheters out wherever possible and also moving into the continence promotion by reducing the number of people who are using pads. So it’s looking at why they’re using pads, how long have they been using the pads for, and making more use of the therapists and doing joint visits with nurses and therapists. So say somebody started off with a problem when they cough, it may be reversible and exercises can help get control back. Some of it would be therapists, some of it would be the nursing and some of it would be the continence nurses as well. Sometimes it will come to the GPs with medication, if you’ve got an overactive bladder and things like that, so it’s actually looking at why the person is incontinent, not, oh, they’re 86, give them pads!”

The link between diabetes and continence is another potential route to address prevention as well as management of continence that may be around urgency. While national targets do not focus on continence and rather, the emphasis is on controlling blood sugar levels, it was recognised that it is potentially an area that where prevention could be addressed:

> “We tend to focus on the diabetic control, but I can absolutely see the link that it is potentially that people are suffering from incontinence because of the blood sugar levels being very high. Maybe urgency in having to go to the bathroom, that kind of thing, so there is a link and currently we don’t actually have close links to SCN’s and when you emailed me I thought this is something that potentially we could, you know, there’s a few teams where we’ve got cross issues. So it’s definitely worth exploring, within the diabetes pathway, if someone is symptomatic from that perspective, you know, is it a diabetes related issue with their continence or something else? ... And some of the newer treatments for diabetes, there’s a new one the (medication name) and the way that they work means that the person tends to be going to the toilet more frequently. So if someone is having incontinence issues, then that’s probably not one of the better medications for them to be on. I think including continence in a checklist of things to talk to a patient about is something we definitely need to consider and probably we don’t currently consider enough.”

Needs rather than wants-led support

The message around any support provided being needs led was emphasised by most service providers across health and social care:

> "The key question is: what is the need? How can we best meet the need? We've tried X, Y and Z. We know there aren't any pads that could contain that much fluid overnight, but we could look at what's the last time for the night call and how early the next visit can be made in the morning".

The example of 'pull ups' was shared as often being perceived as a 'preferred product' by many, even though the absorbency is less effective and therefore unsuitable. The fact that the pads are more expensive emerged as a secondary yet significant issue, but discussion with service users and carers has demonstrated that pull ups are regarded as being more like pants, so are perceived as 'normalising' the continence issue to a greater extent than the other types of pads, which are regarded as being more reminiscent of (and sometimes described as) 'nappies', so are seen as infantilising and less dignified.

> "Now I'm getting pads provided but I'm not happy with them.... they're nothing like I get when I go to Boots Chemist, and you just put your feet in them and pull them on and that's it, they're done. But I can't get those ones...I asked for them in the hospital and they don't do them.... I think the government won't pay for them".

Such issues around service users preferring certain products that are less suitable than the prescribed product has emerged as something of a challenge, and it may be that more detailed explanations as to why certain products are preferable would help patients better understand such decisions. Service users, such as the above quote demonstrates, report feelings of frustration that restrictions are made on the numbers and types of pads provided and feel this compromises dignity and wellbeing:

Needs rather than wants-led support

> “In terms of incontinence, I’m worried about managing because my leg isn’t so good right now; I’ve had re-constructive surgery and since then I’ve had 2 operations which weren’t successful and I’m only partially weight bearing so I’m due for another op. I’m using more pads now than ever before and I’m still waiting to hear from them because I’m having to buy pads myself to keep up; with the help of the family and have been doing so for the past few weeks. The quantity they’re sending is not enough, they’re sending a box of pads to last 3 months!”

An example provided by the Specialist Neuro Nurse demonstrates that it is sometimes the case that education around use of pads is the key rather than insufficient numbers or types of pads:

> “...someone with a brain injury may become distressed if there is any soiling on a pad, and feel they need to change it immediately. The patient may not understand that construction of the pad means that the absorbency will ensure the skin is not in contact with any matter, so the pad will not need to be changed more often than recommended, but patients may need to be reminded about this several times.”

Time pressures experienced by District Nurses may create challenges around spending time checking a patient’s understanding, and taboos around discussing such issues may mean the subject is avoided by patients and their families.

There was also a gender issue identified whereby men are potentially more likely to feel distressed about soiling than women, who will have managed menstruation and are therefore often less squeamish about seeing a soiled pad.

Use of Pull-ups tends to be more focused on people with cognitive impairment, but there was agreement that there always needs to be an assessment in each individual case:

Needs rather than wants-led support

> “... for service users who’ve got cognitive impairment and can mimic what they’ve been used to, it’s fine, but for a service user who may be more confused and can’t, and are incontinent full-stop, they can’t even remember that they need to pull the pad down to get to the bathroom, so then it really is inappropriate for them...”

If the need is primarily an inability to mobilise to reach a toilet or commode, there are other innovations that might make support from care staff the best option in terms of health and wellbeing. The additional funds that can be accessed may enable people to purchase support, and whereas previously hoists required two people, there have been advancements in recent years:

> “There are single-handed hoists that are being used, because we’re moving into smarter care, so there is equipment that historically two people would use, but now they’re building down to one person being able to use the equipment”.

Interestingly, the introduction of charging policy was seen as an incentive by some to support motivation to work harder to retain independence. As a Reablement service colleague pointed out:

> “...a lot of people want to retain their independence, and that’s what we do, we try and give them back that. When the charging policy came in, we said to them, “Work with us, and you may not need to pay for this, because if we can get you into a routine, get equipment in for you and you’re able to have your personal care without needing support, then you won’t worry about having to pay! So it became a good motivation for people to engage with Reablement, because it’s free for up to six weeks, so you hope that people would engage a lot more because after six weeks they could be financially assessed and might be asked to make a contribution.”

Emotional support

Where continence is the primary problem, people may find it harder to access psychological support than if part of a pathway e.g. Neurological or Respiratory pathways. The main route for accessing psychological support, if not on one of these specialist pathways, is through GP's and through Improving Access for Psychological Therapies Service (or IAPT). This national programme has been going for a number of years and aims to improve access to Mental Health Services at primary care entry level, and the service has recently transferred to ELFT.

IAPT focuses on anxiety and depression as it presents in primary care, and while the main focus originally was on supporting working age adults living with anxiety, depression, or low mood, (as these psychological factors were identified as preventing people from engaging in 'meaningful occupations'), this criterion has recently broadened to include those living with long term physical health conditions, including older people. IAPT employs Mental Health Workers in primary care settings to offer individual and group sessions, and Community Psychologists will signpost via the GP for people who they identify as benefitting from IAPT. There are national drivers which mean IAPT have to see a target number of patients, and the mental health workers employed to support people through IAPT are less well qualified than psychologists, so anyone with more complex needs would be referred to Clinical Psychologists:

> "...there would be clinical psychologists within that service supervising other staff who are psychological wellbeing practitioners. They do Cognitive Behaviour Therapy (CBT) mainly; IAPT is very much about CBT... they do use other models of psychological therapy as well, but when it first came out IAPT was focused on using the evidence base for CBT: how to deal with your anxiety, how to stop avoiding going out, and build up slowly. Some people do benefit from a fairly surface-level intervention and then get on with life; they don't necessarily want or need that long term engagement it seems. Or they might do that one year and then come back and do something again in five years' time if they need a top up."

Emotional support

The impact of continence issues on relationships was illustrated by the following extract from an interview with a 78 year old man with a catheter:

> "….. I'm 78 and can't have any intercourse due to the catheter… ….. nobody talks to me about how I feel. I know my problems are probably trivial in comparison to others but they should still give some importance to me as I am suffering. I guess I just have to wait and see."

The Head of Community Psychology suggested that support should be available via signposting to an alternative pathway:

> "… In the case of sexual dysfunction, I would contact the Sexual Health Service; we still have a Sexual Health Psychology Department, based at Ambrose King Centre. Urologists should know this, but they may not, and I guess urologists probably see hundreds of people a year, they wouldn't refer all of them….."

The possibility of ageism was also raised in relation to societal expectations:

> "If the person is younger, they would be asked, "Do you want to be a father? Have you got a sexual partner?" Whereas at 78, it's easier not to mention it… also, people can be ageist about themselves, as well, so they probably won't consider being referred to a Sexual Health and Dysfunction Clinic ….."

The inability to access help may in some cases lead to a downward spiral of social anxiety and isolation which can lead to loss of wellbeing. The impact of products on relationships and emotional wellbeing and self-esteem was an issue that came up several times:

> "They did suggest pelvic floor exercises which I've been doing for years but I think my pelvis is gone altogether…. every now and again I wet the bed. They did offer me pads but I don't like to wear them because they're really big and even with jeans on my backside will probably look like Kim Kardashian. I mean I'm not big and even then the pads are too big for me … I don't know how they measure the sizes but I try an avoid using them when I'm going out walking".

Emotional support

The Community Psychologists are in the process of piloting an 18 month project in partnership with GPs in Network 2 (Brick Lane & Whitechapel) and Network 7 (Newby Place):

> “….they see patients with long term conditions from those networks and they both know lots of GPs and are focusing on COPD and diabetes, because demographically speaking they’re the most common long term conditions in TH (and I think England) and so we’ve given them one each to focus on, but really they’re interested in long term conditions in general … I mean, it’s only two networks out of eight, but they do know all the GPs, and so they might be able to support patients … if you’ve got a long term condition, you have an annual review, or Care Planning Review; one improvement they’ve made is that instead of say if you’ve got a couple of long term conditions, you used to have to come to two reviews, they now just invite you to one …… and they treat you like a person… And that’s actually the core of the project that we’re doing, it’s helping the nurses to do those meetings better and include things like mood: are you happy with the way we’re managing your long term condition with you? What can we do differently? …”

The Manager of the SCN service highlighted the particular challenges of accessing support where continence is the sole problem and unrelated to other long term conditions:

> “I had a lady that I saw who had a back operation, myomectomy, and she ended up with urinary and faecal incontinence and she had real psychological damage. I supported her through that and she managed because of the support I gave her. People like that haven’t got any psychological support. She went to her GP and by then she was depressed, so it affected the whole family; she told her husband to go out and marry somebody else, she was an ill person, she can’t do anything again. So things like that, so that was one of the things we were looking at: how can we get these people to just give somebody to support there.”

Emotional support

The SCN Manager has also set up the Continence user group, which is open to anyone who has incontinence. Currently the service is considering a befriending service to match people who are dealing with their condition with those who may be experiencing problems, so they become buddies. This model has been successful where people are about to have colostomies and are matched with someone who has successfully undergone the procedure.

The Diabetes Lead nurse flagged up the importance of giving consideration to diabetes related Continence and wellbeing, and flagged up the value of the referral route to the IAPT service:

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> "it's something actually that is a big quality of life issue for people, so I'm developing some templates and things for the team, and potentially we could add in something around continence and then signpost people if they do tell us that there's an issue"

Practice Nurses have expressed an interest in increasing their knowledge and awareness of continence so that they can introduce continence into health checks (e.g. 40+) more routinely. They have also shown interest in sharing information such as MyPFF (My pelvic floor fitness free App) and signposting to local PFE classes.

There are a very limited number of free PFE classes available in TH, however, as those run through for example NCT or yoga / tai chi classes make a charge, and people on low incomes would find this problematic. There are free parenting classes on offer prioritising first time parents:

> "... you have opportunities to get 4 free parent education classes from the community midwife who is seeing you. If you miss this completely you can access advice on the postnatal ward before you go home.... it's a question the midwife has to ask on the post natal wards; it's a requirement: How's your bladder? How has it been passing urine? Do you feel that you completely empty your bladder when you go? And then they give them advice... our concern is multips have more of a problem than primips, because the more babies you have, it's more important to look after your pelvic floor, and this is what we tend to say to mothers.... it's a reminder, so as you put a toothbrush in your mouth, let that be your time to do your pelvic floor, so you spend some time and you do it while you do your teeth"

Emotional support

However many younger women have said they feel going to a group would help with motivation as well as combatting isolation, but for people with childcare issues, accessing support or care for children to enable mothers to attend can be another barrier to accessing preventative support, and currently there are no free classes in TH offering crèche facilities. Maternity Mates explained:

> "You have to pay. So that's actually excluding an awful lot of people. Other people have said "I could afford the £5 for that, but I can't afford for the kids to be looked after by somebody in order for me to go to it!" We get that sort of thing all the time."

Voluntary sector groups are often a first point of contact. This can be when people who know the person well notice there is a problem and offer help to signpost for support. Currently the Specialist Continence team deliver one class per month in the community, but capacity is an issue as the team are small and very much in demand.

During the course of bringing together partners across the Alliance, an offer to host preventative PFE or awareness raising classes was made, should there be an issue with identifying premises, and there was agreement about the merits of delivering support in a community setting. Trust established over time between Voluntary Sector groups and members of the community mean that they may be ideally placed to not only identify an issue in a more timely way, but to offer signposting to specialist support. It could be useful to explore those other than the SCN's with potential for delivering preventative classes. Maternity Mates expressed a desire to work in partnership to reach at risk women:

> "If they could do one drop-in session a month, that would be beneficial. We can work together on that. Also we could cascade it and let people know about the phone apps. But they don't all have access to them....to Smartphones .... the midwife could then feel confident about being able to deliver a session for the next lot of volunteers, and so it goes on, so at least like every three months if they provide us when we have all new volunteers. And because we have the project with Queen Mary's, as somebody is being tracked over a period of time if they don't develop any continence or bladder problems, it shows the value."

Communication

More generally, there have been requests across the whole system for a variety of flow charts to clarify the existing pathways for Continence. This includes relevant parties having phone numbers and contact details for the SCN Team, and links to the ELFT and Barts Health intranets with up to date details of the Continence aids policy, as well as a flow chart regarding activating the delivery system for pad delivery/options around keysafes to enable access for those who are unable to answer the door etc.

A patient described some of the issues and problems:

"…. they used to deliver the pads three months at a time, but I think they're cutting down on expenses, so you now get six months. My problem is more with where to keep them rather than the incontinence because my flat is crowded with cartons of pads! (slight laugh) I mean the cartons are about this tall from the floor and about so wide…."

A carer felt there was inadequate information about the cause of the problem:

"My father was put on some tablets for his prostate which later on I learnt was affecting him passing his urine and led to his incontinence and no one explained this link to me early on. He was just put on pads with no other options. I asked so many questions and received little or no answers. Rather than taking him off the pads they have in return provided him with more. There was a time where they did a telephone assessment of his incontinence via asking me questions and it just boiled down to pads again and initially ordering and getting the pads delivered was quite complicated."

Communication

There has been a suggestion that consideration be given to reintroduction of the former practice whereby Community Nurses were equipped with model “Continence Packs” to enable them to share and demonstrate what the most suitable continence product or aid prescribed for the individual looks like, and answer any queries around use. However, there was agreement that a prerequisite for this would be provision of training to ensure that the service is needs rather than wants led, and service users did not view this as an opportunity to select their preferred product.

Similarly, care workers employed by the LA would, it was felt, benefit from Continence training, so they view the products as ‘prescribed’. There are many examples that have been shared with the team where care staff have suggested different products for their clients. There have also been instances where they may have ‘borrowed’ pads from one person to give to another in an emergency, but this is undermining the expertise of those who have assessed the continence need and prescribed an appropriate product. The relationship between care staff and service user means that on occasion this can unrealistically raise expectations and give mixed messages that are unhelpful.

Self-management strategies

There can be links between urinary continence issues constipation and diarrhoea, and information about volume and timings of drinks and identification of individual triggers are invaluable to people in terms of managing and preventing longer term continence issues. As part of the work being undertaken by the Continence Champions, 1 to 1 conversations will take place in a timely way with those experiencing problems to prevent ongoing issues and support self-management.

Many people reported feeling supported to regain independence with continence management, such as this person who had input from the AADS Team:

> "...it was only when I first came out of hospital I had that trouble, because I had the commode and I've never used a commode in my life! ... I used to use a pad at night because I couldn't always use the commode.... I thought to myself, I've got to get in and out of bed and I'm downstairs on my own, and if I fall again... I'd just got it out of plaster of Paris. I thought I'd rather use something so that I can stay in bed....so I used a pad. But I mean, that's all right now, the incontinence, that's all fine".

People living with long term conditions also reported feeling well informed by the Specialist Continence Nursing Team, such as this MS patient:

> ".....Now I have a tablet that reduces the bladder spasticity; I still get spasms and tingling, but I think it tightens up the bladder. I mean, my wee is much more in control now. I know now when I've got to go, I go, whereas before I would hold, and if I'm going to an event, I'm very cautious now what I drink, especially if I'm out and about. I must confess, I never wear now light coloured trousers, so ....if I ever squirt, you know, you wouldn't quite see it. I mean I used to wear lovely nice proper trousers, I mean these are lovely anyway for older people, but I now just wear black down below. I did not feel any embarrassment...and I didn't feel anxious or anything, because I was in a warm supported, professional environment. The nurse was lovely, you know, even though she was a woman I didn't feel any embarrassment...."

Self-management strategies

Carers also reported feeling supported:

> "...It was at a screening and the person who assessed her was very kind and they did a fantastic job, because actually they identified other problems with her incontinence that were sorted over a period of time, and which was really that she was not processing enough urine, and we got her into different drinking patterns and we cured the infection, which was there because of the continence problem. They did very well. They sorted out massive problem, and I'm really massively grateful for the service we received."

Other service users with complex health issues expressed their gratitude for the ongoing support provided:

> "I've been under the Continence Service for some years now. I have a growth behind the gall bladder and the liver which is inoperable because they told me it would kill me to try and do anything about it. It was affecting the bladder and I was referred to the Incontinence Service and for a number of years now, I've been seeing a lovely nurse at Bancroft Road Hospital... she's been absolutely marvellous with supplying pads and things like that...They give me a CT scan regularly, once a year, to see if anything has worsened or improved there, but so far it's been stable for about three to four years. The nurse there is marvellous, absolutely marvellous. I see her regularly once a year, but if I start having any other problems, I've been told to ring her straight away."

> "I have MS and when I first needed the Continence Service, I accessed help through the hospital and I've been happy. If I had a problem with the actual products, I'd phone the company, I've got that phone number for the suppliers, and I have phoned them when the deliveries went wrong a couple of times and they sorted it out. But if there was a change in my physical condition I'd speak to the GP."

Self-management strategies

Raising awareness of the need for public toilets

One major issue is the decline in the number of public toilets that are free and accessible. This has impacted on people who are suffering from continence issues such as urgency, and there seems little appetite for discussing the issue because of the taboos. The Great British Public Toilet map was developed by the Helen Hamlyn Centre for Design at the Royal College of Art to identify the location of not only public toilets but any cafes, pubs or restaurants that allow people to use them without making a purchase. There is also information about disabled access and other details that may be helpful. While this is a very helpful resource, the information requires regular updating, as, having tested out some of the local signposting; several of the toilets mapped now make charges or have closed altogether. Such a site is really only accessible to those with devices where it can be downloaded, but also requires long term investment. Again the challenge is likely to come down to the fact that nobody regards toilets or matters of toileting as very appealing so is hard to attract funding.

In London the Mayor of London, Sadiq Khan has pledged to address the issues, and plans to provide ‘Changing Places’ toilets. These are different to standard accessible toilets as they are built for people who may have limited mobility and need specific equipment or the assistance of carers, and are also larger than standard disabled toilets as well as having additional features including a height adjustable changing bench, height adjustable sink, toilet designed for assisted use, and a hoist. For the first time, the London Plan also calls for the provision of gender-neutral toilets, to help Trans and non-binary people feel more comfortable.

> “I have vowed to be a Mayor for all Londoners so I am determined to ensure that everyone has the ability to enjoy our great city to its fullest. “Toilets are a vital public service and can help to shape the experience of the capital for those who live here and for those visiting. We need a range of toilets that reflect the incredible diversity of this city – giving people the confidence to move around London with dignity.”

Self-management strategies

Tower Hamlets has a map available through the TH council website and called 'clean and green' that maps local toilets, but this is fairly hard to use. TH has more public toilet facilities than neighbouring boroughs, but most make a charge and there are fewer open doors establishments offering free facilities when compared to the City. It is easy to see and understand some of the challenges that may discourage cafes and pubs from taking part in initiatives to open their toilets free of charge to all (such as substance misuse and other inappropriate use of facilities) but initiatives in Camden for example, have sought to overcome such obstacles.

Another innovation being offered by the Bowel and Bladder Foundation is a card that uses universally acknowledged W.C. signage, giving the benefit of discrete and clear communication to others for those who have difficulty waiting to use the toilet. There is also a free Just Can't Wait App that locates the nearest toilet, but this is only available to download to iOS devices.

Sainsbury's has become the first supermarket to introduce 'dementia-friendly' signs in all store toilets, thanks to a campaigning pensioner who was repeatedly forced to rescue her husband – who suffered from Alzheimer's – as he tried to find his way to and from the loos.

Appendix 1: links and further information

Great British Public Toilets Map

https://greatbritishpublictoiletmap.rca.ac.uk/

http://www.hhc.rca.ac.uk/CMS/files/Toilet_LoRes.pdf

Bladder and Bowel Organisation

https://www.bladderandbowel.org/

The Bladder & Bowel Community provide over 60 downloadable resources, such as frequency charts, the Bristol Stool Chart, bladder and bowel diaries, and pelvic floor exercises, to name but a few. There is also a section on support such as travel, sexual relationships, and emotions. There is also a document specifically for those supporting their loved ones. There's a number of stories from patients and carers.

Also offer a free Just Can't Wait toilet access card which uses universally acknowledged W.C. signage, giving the benefit of discrete and clear communication for those who have difficulty waiting to use the toilet.

https://www.bladderandbowel.org/help-information/just-cant-wait-card/

There is also a free Just Can't Wait App that locates the nearest toilet, but only available to download to iOS devices

TH map: Clean & Green

Mayor pledges increase in types and numbers of toilets

Sainsburys introduce dementia friendly toilet signage

Causes of problems with catheters:

GLOSSARY of Abbreviated Terms

LA: Local Authority

IAPT: Improving Access for Psychological Therapies Service

SAFER: discharge bundle: The five elements of the SAFER patient flow bundle are:

S – Senior review. All patients will have a senior review before midday by a clinician able to make management and discharge decisions.

A – All patients will have an expected discharge date and clinical criteria for discharge. This is set assuming ideal recovery and assuming no unnecessary waiting.

F – Flow of patients will commence at the earliest opportunity from assessment units to inpatient wards. Wards that routinely receive patients from assessment units will ensure the first patient arrives on the ward by 10 am.

E – Early discharge. 33% of patients will be discharged from base inpatient wards before midday.

R – Review. A systematic multi-disciplinary team review of patients with extended lengths of stay (>7 days – 'stranded patients') with a clear 'home first' mindset.?

SCN: Specialist continence nurses (SCN) with advanced theoretical and knowledge of bladder and bowel dysfunction offer advice, training and an advanced specialist clinical service in the prevention and treatment of incontinence.

(THT) Tower Hamlets Together: THT is a partnership of local health and social care organisations with an ambition to improve the health and wellbeing of people living in Tower Hamlets.

GLOSSARY of Abbreviated Terms

L (ELFT) East London Foundation Trust: Provides a wide range of community and inpatient services to children, young people, adults of working age , older adults and forensic services to the City of London, Hackney, Newham, Tower Hamlets, Bedfordshire and Luton. We provide psychological therapy services to the London Borough of Richmond, Children and Young People's Speech and Language Therapy in Barnet and specialist addiction services in Redbridge. https://www.elft.nhs.uk/

(TWOC): Catheter removal ‘through outpatient trial without catheter’.

(PFE) Pelvic Floor Exercises

(CCGs) Clinical commissioning groups are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England.

N-abled empowered living: We offer a holistic approach to supporting people in their own home who are living with chronic health problems or injuries to become physically and mentally stronger using nutritional and exercise therapy.

(PSHE) Personal, social, health and economic education,

(EPCT) Enhanced Primary Care Teams

(POC) Package of care

(ICU) Intensive Care Unit

(COPD) Chronic Obstructive Pulmonary Disease

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And the following groups:

Alzheimer's Carers Group, Arthritis Support Group, ELFT Working Together Group, TH Carers Forum, The Geezers, MS Support group, Osmani Parent's Group and St.Hlda's User Group

Contact

GP Care Group Patient Experience Team

www.gpcaregroup.org/your-health-services/patient-experience-team/

Contact the team:
thgpcg.patientexperience@nhs.net