Pathways, Practices and Architectures: Containing Antimicrobial Resistance in the Cystic Fibrosis Clinic (PARC)

Interim Key Findings Summary

October 2019

About the study

PARC is an Arts and Humanities Research Council (AHRC) funded project (2018-2020), exploring the implications of building design for everyday practices of mitigating cross infection, comparing three UK cystic fibrosis (CF) clinics. We are examining these issues using creative and qualitative methods, including:

- 70 interviews with 55 participants (34 hospital staff, 15 patients, 3 family members, and 3 architectural professionals):
  - 45 graphic interviews – mapping routes through buildings and perceptions of 'risky' areas
  - 25 walking interviews – following the routes of staff and patients
- 72 hours of observations – observing 'flows' of staff and patients during clinics
- In-situ visual illustrations of patient interviews with artist Lynne Chapman
- A physical exhibition presenting our findings, in collaboration with the Helen Hamlyn Centre for Design (HHCD), Royal College of Art (RCA), presented at: European Cystic Fibrosis Society Conference (ECFS); South West Network for Medical Humanities Regional Event; British Sociological Association (BSA) Medical Sociology Conference; The Helen Hamlyn Research Symposium 2019, RCA.

Project team: Nik Brown (PI – University of York), Chrissy Buse (University of York), Alan Lewis (University of Manchester), Daryl Martin (University of York), Sarah Nettleton (University of York), Mike Brockhurst (University of Sheffield), Lynne Chapman (artist), Craig Winstanley (University of Liverpool)

Collaborators on the design of the exhibition: Hamza Oza and Jonathan West, HHCD, RCA.

For information on further developments and publications, see: *http://parcproject.org.uk*

- Staff and patients at all three sites stress the **importance of a dedicated space for CF outpatient clinics** (only one site had a dedicated CF space). This allows a sense of 'ownership', enabling staff to adapt the space to the specialist requirements for CF care (including appropriate signage, dedicated clinic equipment, and sanitary facilities). For patients, being in a non-CF space (e.g. outpatients waiting area) can have implications for feelings of stigma (see patient story 1).
- The **potential for the transmission of infections indirectly through equipment, surfaces, and airborne bacteria, is managed through a range of strategies**, primarily: cohorting patients (see below); staggering appointment timings; ordering appointments with 'bad bugs last'; 'resting' rooms between patient appointments; opening windows; cleaning surfaces and equipment; using disposable equipment (e.g. stethoscopes, spirometer mouthpieces) or separate equipment (e.g. oximeters, spirometer flow heads) for patients with different bugs; handwashing practices (see below).
- The **ratio of rooms to patients** has important implications for managing cross infection. In busy clinics with a limited number of clinic rooms, it can be difficult to **'rest' rooms or clean surfaces between patients**, with potential implications for the transmission of airborne bacteria. Accessing adequate clinic space can be **challenging in outpatient departments shared with other services**.

Patient story 1: Isobel[1] (age 53, site 3)

Isobel was diagnosed later in life. She has been coming to the clinic at Site 3 for nine years. Isobel describes the CF service as very personalised and the staff as caring: **'the help they've given me has been amazing'**. The CF outpatient service is based in a general outpatient department, using different rooms on different days. Although the CF team try to organise appointments to minimise waiting, Isobel sometimes has to **wait in a large waiting room** shared with the wider outpatient department. She feels **stigmatised and visible** in this area: '**you get tutts, you get sighs** because you are coughing all the time...people will physically move'. She normally comes with her husband which makes her feel less self-conscious. Isobel feels having their '**own CF clinic with its own waiting room**' would remove these issues. Isobel sits in the adjacent café area rather than in the shared waiting area, because the individual tables help to create distance from other patients, in contrast to the bench seating in the main waiting areas.

Isobel talks about getting 'comments' or 'looks' when using the disabled parking spaces, because CF is not 'visible'. She **adjusts her journey through the building depending on how she is feeling** – if she is feeling well enough to walk, she will use a more distant toilet away from other patients. Using the side entrance enables her to cut out the long walk through the corridor if she is feeling unwell, and there are seats where she can wait for her husband to park the car.

- The **segregation of patients differs across clinics**. While all clinics segregate patients infected with the *Burkholderia cepacia complex* ('cepacia'), the cohorting of patients with *Pseudomonas aeruginosa* varies: *Pseudomonas*/*Pseudomonas* free (site 1); chronic *Pseudomonas*/intermittent *Pseudomonas*/*Pseudomonas* free (site 2); segregation of a transmissible strain of *Pseudomonas* (site 3). Two out of three sites segregate patients with *non-tuberculous Mycobacteria* (NTM) such as *Mycobacterium abscessus*, and one site cohorts patients with different variations of 'cepacia' (e.g. *Burkholderia multi-vorans*). This is shaped by local factors (e.g. number of patients, availability of clinic space, local strains of *Pseudomonas*), as well as different interpretations of research evidence. Staff report that it is impossible to cohort for all variations of bugs.
- The **movement of staff and patients is organised differently** across clinics. Sites 1 and 2 operate the **'carousel' system where a patient stays in a clinic room** and members of the multidisciplinary team (MDT) go in to them in turn. In site 3 patients visit members of the MDT in different clinic rooms. There are different views on this – the carousel may reduce the risk of patients crossing pathways, but appointments can take longer. It is also difficult to organise where there is a high number of patients relative to available rooms.

[1] Patient names have been replaced with pseudonyms for anonymity

- **Patients speak very highly about the personalised care they receive from their CF teams –** staff are described as 'caring', 'like a family' and 'dedicated' (see patient stories). This personalised care **can be in tension with trying to keep patients segregated** – patients appreciate flexibility with appointment timings, in light of the fluctuating symptoms associated with CF. However, patients arriving early or late can disrupt carefully planned appointment schedules.

- The **wider hospital journey** is important. Shared spaces including lifts, corridors, cafes, hospital entrances and atriums are described as potentially 'risky' areas where pathways can cross and are difficult to monitor. **CF patients actively manage their pathways** to maintain segregation e.g. 'hanging back' at potential 'crunch points' (e.g. ward entrances, lifts), and sitting apart from people in shared spaces (e.g. cafes, waiting areas). Staff, in particular nurses and healthcare assistants, **carefully monitor corridors and waiting rooms** to ensure that patients do not 'congregate' together. Having **dedicated healthcare assistants** is important to maintaining segregation (see patient story 2).

Patient story 2: Rupert (age 20, site 1)

Rupert has been coming to the clinic at Site 1 for twenty years since he was a baby. He says **'I love my CF team'**. He describes the service as **'so well managed'** in terms of segregation, that he has never met another CF patient. When he comes into clinic he likes to sit near a window, and the CF team normally have it open ready for him: **'I'm big on fresh air, I always go by the window.'** However, he feels that the **building could be improved**. Outpatient appointments at site 1 take place on the ground floor in a busy outpatient department in a 1970s built hospital. The crowded hospital atrium is an area of concern for him: '**anywhere where people congregate they might be coughing**...' Although the CF team direct patients straight into a room, they **do not have dedicated healthcare assistants**, and the **outpatient healthcare assistants sometimes direct him to wait in a seating area** in the busy corridor.

Inpatient and 'ad hoc' appointments take place in a general respiratory ward on the third floor of the hospital. Rupert uses the stairs because of concerns about cross infection in lifts. He is concerned about **walking past the ward bays** on the respiratory ward and hearing people coughing: **'I always walk on the other side of the corridor'**. He feels that the service could be improved if the CF team had **'their own specific CF ward'**.

- **Shared awareness of CF and cross infection across the wider hospital staff** is vital, for instance, during referrals to other departments such as X-Ray or phlebotomy, and among ancillary staff (e.g. administrative, cleaning and portering staff). At site 2, long term working relationships and visits from the CF team to staff meetings (e.g. portering 'safety huddles') has helped to create this awareness.

- At sites 2 and 3 **patients infected with *cepacia* sometimes feel marginalised** due to their segregation from the main CF inpatient wards (see patient story 3). They report that being based on a standard hospital ward means they lack the specialist care and facilities available to other CF patients. Patients infected with ***methicillin-resistant Staphylococcus aureus* (MRSA)** sometimes describe a similar sense of marginalisation and stigmatisation.

Patient story 3: Amy (age 40, site 2)

Amy has been coming to the CF clinic at Site 2 for 26 years, she describes the staff as being **'like family'**. Site 2 has its outpatient services at a small **outpatient hospital**, with a dedicated area of the building for CF. Amy says that **'there's a feeling of safety attached to this place'**, it is **'very accessible', with convenient parking, everything on the ground floor, and a short 'straightforward' journey** from the entrance to the CF area.

In contrast, she describes the **teaching hospital** where inpatient services (and 'ad hoc' outpatient appointments) take place **as 'stressful'**. She worries about **using lifts** and being 'trapped in' with other patients, and the lifts frequently break down. As a patient with ***cepacia* she uses segregated lifts** at the back of the hospital, and has to make a **journey through another ward** which is often locked. Because she has *cepacia* she is in a **separate ward away from the main CF ward**, which she feels lacks the specialist care and facilities available to other CF patients.

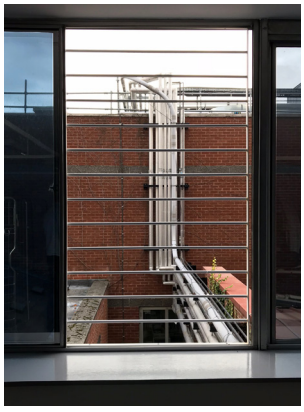
- In sites 1 and 2 **ad hoc appointments** (e.g. for IV lines or urgent appointments) **take place on CF inpatient wards**. This can create challenges for segregation, and potential for outpatients and inpatients to cross pathways, particularly as there is only one way in and out. Patients sometimes congregate at the nurse station to **'catch up with their favourite nurse'**.

- **Handwashing has important symbolic (as well as infection prevention) implications.** Some staff and patients feel that staff washing hands in front of patients is important for visibly demonstrating cross infection mitigation, but some staff are concerned that washing hands in front of patients immediately after shaking hands or a non-clinical consultation could **make patients feel 'dirty'.**

- **Clinics vary in their use of protective clothing** – at site 1 all clinical staff wear disposable aprons, at site 2 and 3 staff do not routinely wear aprons or gloves when treating outpatients unless conducting clinical procedures or treating patients who are in 'source isolation'. Staff feel there is a lack of definitive evidence, and a difficult balance between preventing infection and implications for stigma.

Areas of concern	Potential design implications
Lifts – lifts are an area of concern because they are an enclosed space, and patients entering the lifts from the ground floor do not know if another person waiting for the lift is a CF patient. Segregating lifts is difficult, because lifts are not always in working order.	**Ground floor access** is important in designing new clinics, to avoid problems with lifts. Some clinics have **segregated lifts**, but this does not always work, as **lifts break down**, and alternative lifts may be inconveniently located.
Toilets – shared hospital toilets are an enclosed space that is often poorly ventilated. One patient may use the toilet after another without realising, creating potential for cross infection. Although clinic rooms may be cleaned between patients, toilets are not.	Some new clinics (e.g. Nottingham) have **en suite rooms**. However, this is **costly to retrofit** into existing buildings, and there are resource implications in terms of **cleaning**.
Waiting areas – although clinics try to eliminate or minimise waiting, patients sometimes arrive early or late, and appointments can take longer than expected. There are various **points of waiting throughout the hospital journey** that are hard to manage e.g. **pharmacy, phlebotomy, X-Ray**, or waiting for transport by main entrances.	Some new clinics are being designed **without waiting areas**, but it is difficult to remove waiting from the hospital journey. At site 2, **segregated waiting areas** (one patient in each waiting area) are used to manage the risk of waiting. Site 2 has a **'priority' system in X-Ray** – appointments are booked electronically, then CF patients are given a paper priority ticket to hand in. Approaches used in other European CF centres to manage queuing in **pharmacy** include: an **electronic order system**; **texts** when prescriptions are ready; a **segregated waiting area** in pharmacy for individual CF patients (although this might not work for larger clinics); **home delivery** of prescriptions.
Entrances and Exits to wards or hospitals are points where pathways can cross. Patients express concern about waiting to be buzzed onto a ward, touching buttons, door handles, or proximity with other patients in entrances with revolving or double doors.	Some clinics in the UK have a one-way system, where signage directs patients to come in and out via separate routes. However, people do not always move through buildings as directed, and may just **take the shortest route**. An infectious disease hospital in Malmo, Sweden has separate entrances to each inpatient clinic room from the outside of the building. However, this is **challenging to retrofit** into existing hospital buildings, and has **implications for security and maintenance**.
Lack of storage on wards means that other spaces have to be commandeered to store equipment (e.g. bathrooms, gyms, corridors, stairs) and can become **'cluttered'**. For cleaners, this makes their job more challenging, with implications for mitigating cross infection.	**Adequate storage space** being built into the design of inpatient and outpatient services. Storage is often cut in the design process.

Areas of concern	Potential design implications
Ventilation – outpatient CF areas (and sometimes inpatient wards) in our study do not have specialist ventilation, although most clinic rooms have openable windows.	**Negative air pressure** is recommended for the design of inpatient facilities to manage the risks of NTM (CF Trust 2017), but the **cost can be prohibitive**, and clinicians expressed different views about the relative benefits. Patients enjoy the **sensory experience of being next to a window**, but sometimes windows cannot be opened in rooms overlooking outside areas where people smoke nearby. **Regulatory requirements for window restrictors** in hospitals (e.g. see Health Building Note 00-10) limit window opening. At site 1, the estates department had created a 'work-around', with horizontal bars on windows set out 100mm apart so large sliding windows could be opened fully, while meeting regulatory requirements.
Corridors – patients and staff are concerned about the potential for pathways crossing in narrow corridors, particularly if patients come in and out the same way. There's also a lot of equipment (trolleys, observation machines, mobile work stations) that has to fit into and move through corridors	**Wide corridors** are important to avoid close proximity between patients, and to accommodate equipment and trolleys. Are there ways of reducing the journey from the entrance to the CF clinic room, to limit the risk of patients passing?
Cafés and restaurants – staff are concerned about patients using cafés and the potential for queuing or congregating together. However, patients are often careful when visiting cafés to sit at a distance from other people, and to avoid busier times where possible.	Site 1 uses **food vouchers** to encourage patients to use the larger **canteen, rather than the coffee shop**, which is more spacious, with tables and chairs spread out. Specialist CF clinics are being built **without café areas**, but patients might still use the cafés in the main hospital. Being able to access refreshments can make outpatient hospital visits **more pleasant and 'hospitable'** for patients and relatives – is there a way to provide this while avoiding the risks of shared café areas?
Parking – patients report difficulties accessing nearby parking spaces, and negative responses when they use blue badges, due to the 'invisible' nature of CF. This is particularly challenging for patients who visit their CF clinic alone. Parking during long inpatient stays can be expensive. Touching buttons on parking meters was also a concern for some patients.	Site 1 offers stamped parking permits to CF patients for free parking. Site 2 has three dedicated CF parking spaces for inpatients, but there is still a lot of competition for parking.



Cover image and other sketches by Lynne Chapman www.lynnechapman.net

UNIVERSITY OF LIVERPOOL

The University Of Sheffield.

Royal College of Art
THE HELEN HAMLYN CENTRE FOR DESIGN

UNIVERSITY of York

Arts & Humanities Research Council

MANCHESTER 1824
The University of Manchester

Department of Sociology
Wentworth College
University of York
Heslington, York
YO10 5GD
york.ac.uk/sociology

47292 – york.ac.uk/designandprint