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Experiential and environmental dimensions of inpatient isolation bedrooms

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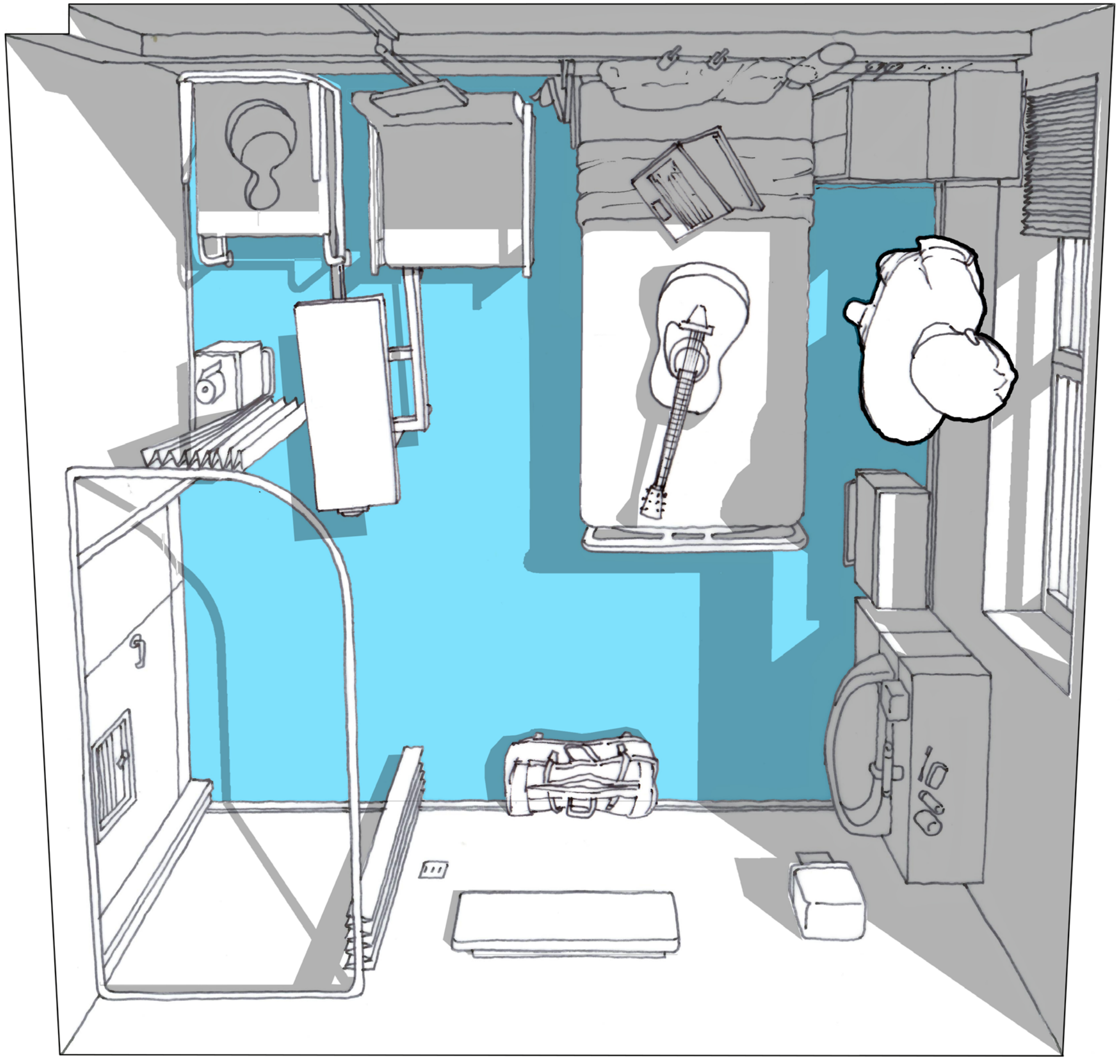


Contents

1 Preface 3

2 Abstract 4

3 Introcuction, background, aims and objectives 5

4 Current context 6

5 Study methodology 8

6 My patient experience: An auto-ethnographic account 10

7 Patient feedback, early findings 16

8 Discussion 18

9 References 20

1 Preface

In 2020, I was diagnosed with Leukaemia. My treatment regime required me to reside in hospital isolation for three weeks while I received stem-cell transplantation.

The turmoil I experienced was both physical and emotional. Enforced isolation for several weeks intensified all the fear, despair and uncertainty connected to being confronted by this life-threatening illness.

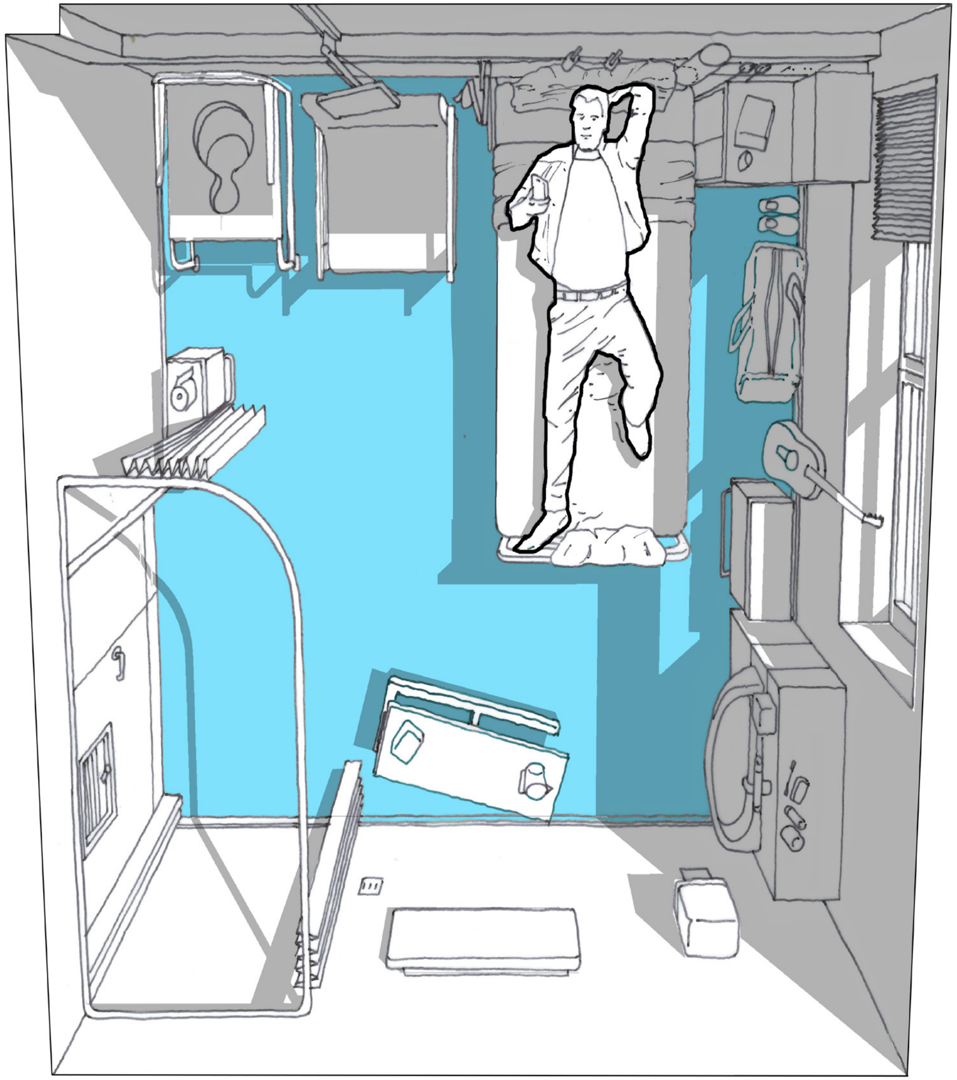
From a design perspective, the current provisions for an immunocompromised patient in the UK are wholly inadequate and, along with supporting design guidance, need a serious refresh.

While recognised as a necessary tool to avoid serious infection risk, the practical purpose of the isolation room can belie its psychological and emotional effects. To counteract this, the room design should prioritise human wellbeing and adopt an approach that recognises these special circumstances.

However, this is rarely the case. The guidance which informs design consistently fails to differentiate these spaces from other inpatient spaces and places emphasis on technical issues such as air-quality rather than on sensory or affective matters. In some respects, the isolation room can be seen as a spiritual setting – it is a room in which the deepest of thoughts are inescapably and relentlessly revealed day after day after day. What would seeing it in this way mean for design?

As part of my PhD, I'm seeking to explore the experience of other patients undergoing cancer treatment to inform practices of 'person-centred care'. Recognising that clinicians may increasingly be encouraged to ask: 'what matters to you?' rather than 'what is the matter with you?', I hope to unpack the implications for the design of spaces for inpatients in hospitals, especially isolation rooms. The drive for a 'person-centred' approach to design emerges with a need to prioritise being more 'sense-sensitive'.

This paper summarises my interim position as my research continues. I'd like to extend a huge credit to my Professor Juliet Davis who has contributed to this paper and continues to support my research.



2 Abstract

The experience of a patient undergoing cancer treatment in a strict isolation setting is not just physical but can also involve emotional turmoil. Enforced isolation for several weeks itself can induce emotional reactions added to which are the fear, despair and uncertainty connected to being confronted by a life-threatening illness and by a sense of mortality. Isolation of course is widely recognised as a necessary tool to avoid serious infection risk, but the practical purpose of the isolation room can belie its psychological and emotional effects.

One might expect that the design of such a room would prioritise human wellbeing and adopt an approach that recognises these special circumstances. However, this is rarely the case. The guidance which informs design consistently fails to differentiate these spaces from other inpatient spaces and places emphasis on technical issues such as air-quality rather than on sensory or affective matters. In some respects, the isolation room can be seen as a spiritual setting – it is a room in which the deepest of thoughts are inescapably and relentlessly revealed day after day after day. What would seeing it in this way mean for design?

The research for this paper begins with personal experience as a patient coupled with many years designing healthcare facilities. It seeks to explore the experience of other patients undergoing cancer treatment to inform practices of ‘person-centred care’. Recognising that clinicians may increasingly be encouraged to ask: ‘what matters to you?’ rather than ‘what is the matter with you?’ it seeks to unpack the implications for the design of spaces for inpatients in hospitals, especially isolation rooms. The drive for a ‘person-centred’ approach to design emerges with a need to prioritise being more ‘sense-sensitive’.

3 Introduction, background, aims and objectives

3.1 Introduction and background

All spaces designed for human habitation are human-centred in some way whether they be spaces for learning, working, shopping or entertainment the particular needs of occupants and how their activities are supported have to figure highly in the designer's approach. Spaces for treatment and healing perhaps demand an elevated level of design consideration with a greater focus on the occupant and their needs. When one begins to consider a hospital bedroom, in a scenario where the occupant is forced to remain exclusively within the room for an extended period, the demands for an appropriate design response extend to an even greater level.

The inpatient isolation bedroom is a patient room which caters for some very specific needs. Recognised for many years as the primary means to protect a severely immunocompromised occupant from harmful sources of infection, the isolation bedroom has become a key component in treating a patient with a blood cancer where transplant of the bone marrow function (through replacement of 'stem-cells') is seen as the only option for survival. A room in which the occupant not only has to face significant physical and mental challenges given the nature of diagnosis and treatment but also has an added functional dimension in that strict isolation practice typically extends to three or four weeks as a minimum. This room perhaps has a responsibility to perform in ways that other standard inpatient spaces do not. One would assume therefore that its design and the guidance literature published to safeguard its performance would recognise these special set of circumstances. This research seeks to explore this issue and to establish if the special human-centred requirements, so essential in this context, are addressed.

This paper represents a summary of activities and initial findings based on partial completion of a wider PhD study. The study has so far focussed on a review of literature and completed some complex processes relating to NHS ethical approval. An initial approach to the development of a detailed methodology has also progressed.

Whilst only at an interim state, the progress and findings to date have some value and are useful in developing discussion.

The genesis of this study comes from the combination of experience as both a design professional and as a patient. Having spent twenty-five years as a practicing healthcare architect I thought I had amassed all the knowledge I would need to design spaces for healing. Only through undergoing treatment for leukaemia and receiving a stem-cell transplant in 2020 within an isolation bedroom, did I realise there were many critical experiential factors that were commonly overlooked. My research to support a PhD study into these topics has highlighted that provisions for the immunocompromised patient are wholly inadequate and, along with supporting design guidance, are in need of review and refresh.

3.2 Aim and objectives

The aim of the study is to understand the environmental needs of adult immunocompromised inpatients and to explore how these are best delivered.

The objective is to consult with former inpatients and current staff about their experience and expectations regarding care within an isolation bedroom and obtain their feedback to inform the exploration of new solutions.

4 The current research context

4.1 Stem-cell transplant, the immunocompromised inpatient and protective isolation

Since Old Testament times and the establishment of leper colonies, isolation has been seen as an effective means of dealing with infection. Patients can be isolated because they present a hazard to others (e.g. Ebola virus or radiation risk during iodine 131 treatment for thyroid cancer) or because they need protection from infection sources due to a depleted immune function. The most common need for patient isolation relates to treatment for blood cancers and the transplant of stem-cells. The mechanics of treating a blood cancer and undertaking a stem-cell transplant is well explained in literature (Sherrell 2021). The pre-conditioning, chemotherapy-induced neutropenia and the wait for neutrophils to return to safe levels all point to an extended period, often at least three weeks, where the patient is at risk of harmful infection due to the re-setting of immune function. During this period, patients are segregated to protect them from infection sources be they from the air, water, other people or food and drink.

A key feature of any isolation bedroom is the mechanism to achieve a pressure differential to adjacent spaces and the provision of HEPA filtration to regulate the air quality within the room and eradicate potential airborne pathogens. This is typically achieved with a lobby arrangement separating the bedroom area from any adjoining room or circulation space, thus allowing a pressure differential to be achieved.

4.2 Design guidance for isolation facilities

NHS design guidance does exist for inpatient isolation bedrooms. NHS England publication HBN 04:01 Supplement 1 (Health 2013) provides specific guidance for the design of isolation bedrooms. The guidance focuses on providing a lobby arrangement, maintaining safe air quality through the use of HEPA filtration and pressure differentials as well as the provision of space for donning of PPE. In all other respects, the room is treated identically to a standard inpatient room in terms of the recommended size (19sq.m). The guidance does make some passing reference to the specifics of isolation in the following clauses:

‘4.20 Accommodation should be stimulating and as comfortable as possible’

‘4.25 The sense of containment and social isolation can also be reduced by providing outside views and using windows with low cills. Internet access for the patient should be provided.’

Whether these references adequately address the challenges faced by an isolated patient is questioned.

4.3 The patient response

The difficulties experienced by a patient faced with weeks of isolation are well documented in literature with the emotional challenge in particular being well described (Coolbrandt and Grypdonck 2010; Barratt et al. 2011; Annibali et al. 2017; Biagioli et al. 2017; Digby et al. 2024). Common reactions include feelings of extreme boredom, high anxiety, anger, despair and frustration resulting in some cases to symptoms of post-traumatic stress following discharge.

Similarly, the response of clinical staff is also well recorded in research with a range of responses including feeling threatened by hostile patients and wanting to minimise interaction (Bendjelloul et al. 2021).

The unique set of circumstances faced by a confined patient (a combination of social isolation and arduous physical treatment) also results in an elevated response to environmental factors. The effects of noise, smell and temperature are often elevated above the norm affecting well-being and increasing the tolerance burden imposed on the patient (Douglas and Douglas 2004; Hsu et al. 2012;

Eusebio et al. 2017).

The difficulties experienced by patients are well documented but the extent to which the design of the isolation room, or the features/fittings within it, contribute to that experience either positively or negatively needs further research.

4.4 The research gap

A literature review indicates that a wealth of material relating to allogeneic stem-cell transplant, protective isolation and the effects of treatment exists (Lee et al. 2011; Matić et al. 2023; Lee and Halliday 2025). However, apart from considerations of air quality and space for barrier-nursing and donning of PPE, there is an almost complete lack of research which has considered how the design of the isolation bedroom itself might alleviate the negative effects of the process. There is no design guidance which specifically addresses either the emotional challenge of isolation or the range of activity which the patient may want to undertake during extended periods of confinement. Nor is there any literature which recounts former patient’s views and experiences specifically about the design of their isolation bedroom. Questions which do not tend to be asked specifically about life within an isolation room include what could they see, what could they do, or not do, in the room, how did sound travel within and into the room, how much connection with the outdoors did the room allow, could conditions within the room be controlled or adjusted? These queries are relevant in almost any healthcare context but somehow have added significance in the context of strict confinement. There is clearly an opportunity to address a gap in the research context and to explore the need for new solutions and how these might be delivered.

5 Study methodology

How to understand the immunocompromised patient's environmental needs?

The study is founded upon an auto-ethnographic aspect which provides useful insight and empathy for the topic and those who are affected by it. From my own experience as a transplant patient and as a design professional in the healthcare field, I can bring a depth of knowledge and connection with this subject which hopefully adds some extra weight to the nature of enquiry. However, whilst potentially interesting, the views and recollections of one person based in a particular location presents an overly narrow approach. It is important to widen the study to a larger range of views from both patients and staff, in several locations.

The work therefore seeks input from staff and former patients from three different UK locations. My own experience is based upon treatment received at University Hospital Wales, Cardiff – a facility built in 1971 and like much of the NHS estate, suffering with significant backlog maintenance issues. Many of my own opinions about the nature of protective isolation therefore relate to some site-specific issues which although not uncommon, might not necessarily be prevalent in every hospital, hence the need to consider other locations. I have therefore engaged with the Bristol Haematology and Oncology Centre and the Grafton Way Building at University College Hospital London. The Bristol Centre was fully refurbished approximately 10 years ago and the London centre is almost brand new. Seeking input from these centres will ensure that any relevant 'estates-related' issues are based upon a range of locations, with different building types and ages. Usefully, this approach allows consideration of some specific matters relating to facilities which are either aged, refurbished or brand new.

Building upon my own depth of experience and knowledge, the study also focuses highly on experiential matters. It therefore favours a qualitative mode of enquiry rather than quantitative. The work seeks to follow the principles of an integrated phenomenological analysis (IPA) and has been influenced by the writings of Simon Watts and others (Watts 2014).   It could be claimed that each of the typical qualitative research methods (grounded theory, narrative analysis) have some relevance here but the application of an IPA would seem to be the best method of achieving the 'person-centred' approach necessary in answering the study's main research aim, particularly given the extent of my own knowledge and experience.

Rather than reliance on tools such as questionnaires or focus groups, the study favours a series of in depth semi-structured interviews with staff experienced with administering allogeneic transplants as well as former patients who have experienced a stem-cell transplant in an isolation room setting. A mixed-method approach to the research design could be useful but targeting a richly detailed data-set where personal individual experience is prioritised is seen as the best way to maintain the desired person-centred focus. There are some practical organisational challenges involved in engaging with NHS staff and former patients to obtain feedback so one-to-one semi-structured interview sessions are favoured over the use of questionnaires and focus-groups, where a greater reliance on NHS staff resources would be necessary.

Guidance regarding the appropriate number of participants in a study such as this is wide and varied (Baker and Edwards 2012; Robinson 2014; Bekele and Yohannes 2022). Target numbers of participants is dependent on the particularities of each study and also the degree to which saturation is necessary. Some useful guidance is provided in the Journal of Qualitative Health Research, which states:

'If when using semi-structured interviews, one obtains a small amount of data per interview question, then to obtain the richness of data required for qualitative analysis, one needs a larger number of participants (at least 30 to 60).' (Morse 2000)

NHS ethical approval has therefore been sought to allow engagement with 20 participants at each of the three hospitals proposed to be involved in the study. In each centre 8 male and 8 female former patients with an additional four staff members (two nurse specialists and two consultants) are invited to participate. This will result in a total of 60 participants, each engaging in an interview of up to one hour. This should be sufficient to provide a significant depth of response across the three different proposed hospital settings.

Participant recruitment begins with a recruitment poster to be displayed in agreed locations within each hospital, focussing on waiting areas for haematology related outpatient clinics and consult/exam suites. This should therefore alert patients who have finished their stem-cell treatment but who may still be attending follow-up checks and consultations to the study. Clinical teams at each participating centre will also communicate directly with former patients who may not be regularly attending the clinic via letter/e-mail attaching the recruitment poster to alert them to the study.

A detailed Participation Information Sheet (PIS) is made available to participants who have expressed an interest in participating having seen or been made aware of the recruitment poster. If having seen the PIS the participant is keen to engage, a one-on-one semi-structured interview session is arranged either in person, or via an on-line platform, to suit the respondent's preference. An Informed Consent Form is provided to each participant and completed prior to commencing the session which is digitally recorded to allow further transcription and analysis. No personal identifying information is included in the recorded data with anonymisation ensured through the use of site-specific pseudonyms (e.g. 'OP1' for Patient 1 from UHW ('Old') or 'NP1' for Patient 1 from Grafton Way ('New')). Each interview is supported by an interview schedule of pre-determined questions and prompts which will help to structure the conversation although the ability for the discussion to veer outside the schedule structure is assumed and not discouraged.

The NHS ethical approval process (NHS 'IRAS') stresses the need for research design to be based upon some degree of input from the public and from patients in particular. Accordingly, notwithstanding my own patient experience, this study has benefited from input from two former patients and a former nurse researcher who have each provided useful feedback and suggestions regarding the development of the protocol and related documents such as PIS etc. Pilot interview sessions have also been extremely useful in developing schedules of questions and rehearsing the interview process. Similarly, early engagement with staff groups at each of the proposed centres has informed the research design.

Reference to my lived experience as a patient undergoing treatment in an isolation setting is useful but clearly has some limitations. Focus on the reflections of one middle-aged, white male, from an upper middle-class background with experience based in one location at a particular time is too narrow to offer meaningful insight. The need to obtain a diverse mix of participants is therefore important. So whilst the study targets a defined number of participants (8 male and 8 female former patients in each centre), the need to allow for saturation and a broadening of engagement is recognised. The input and help from personnel at each centre in recruiting a diverse mix of respondents is key therefore. To best fulfil the core aims of the study, gender, age, culture, ethnicity and neurodiversity need full consideration.

The interview process is also recognised as critical in meeting the study objectives. Some forays into early interview-piloting and rehearsal has highlighted the need for careful attention to bias both as an interviewer and also in participant response where the frailty of recall might arise. Post interview analysis and conclusions therefore need to recognise these potential limitations.

6 My patient experience: An auto-ethnographic account

As above, the ability to refer to my own experience and to reflect upon this as either an architect or a patient adds an extra dimension to the study. It not only introduces an empathetic element to engagement with participants but also underpins the investigation through added knowledge and connection with the subject. It is useful to refer to this in some detail as a means to illustrate some core issues and also to inform the approach to engagement with study participants. The study seeks to obtain a rich spread of experiential data from as diverse a group of people as possible in a range of locations. It makes sense therefore for this exercise to benefit from some deep understanding of the issues that people will have faced.

The value of auto-ethnography as a research method has been written about extensively – it is a useful method but needs careful application (McIlveen 2008; Méndez-López 2013; Bochner and Ellis 2022; Bae 2025). The benefits and potential pitfalls of the approach is usefully summarised by Addyman in a recent paper (Addyman 2025):

‘An advantage is that the researcher is closer to the data both in terms of its meanings and access to it. Living and breathing both practices in real time affords an opportunity to reflexively interact with practice and theory almost simultaneously. The challenge is to become neither so saturated in theory that one loses sight of one’s role, but equally to not become so engaged that one loses sight of the need to act as a researcher on a continuous basis. Maintaining a reflexive account of engagement with self and others while in the field is thus an important aspect of auto-ethnography.’

So the approach adds the potential for deep reflexivity, richer insight and a more nuanced understanding of the topic but the influence of my own positionality and how this affects the research needs careful handling. The intention is to uncover a wide range of experiential responses and to avoid any tendency to engineer situations so my own opinions and concerns are endorsed.

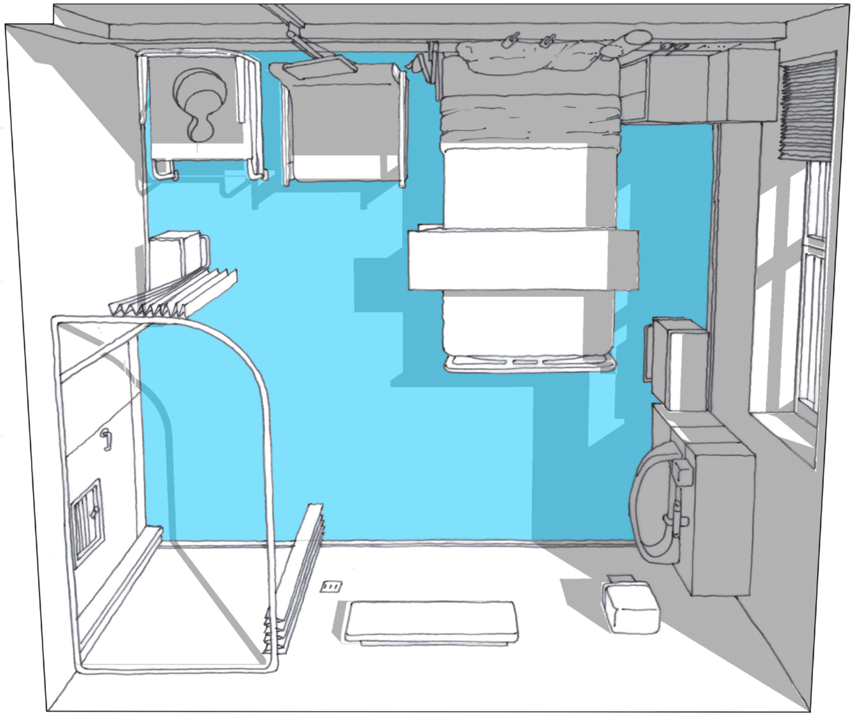
In recalling my own experience I have tried to document this in a more systematic manner. Rather than a simple recalling of ‘issues’ on an anecdotal basis, it is perhaps more useful to attempt a more analytical approach to understanding how the isolation room influenced occupation. Consideration of what I did, using what items or ‘things’, in which part of the space, at different times throughout each day perhaps illustrates the day-to-day experience of isolation in a more meaningful manner, especially when overlaid with thoughts and emotions which were prevalent at the time. Core daily activities have therefore been ‘mapped’ in the space to understand how I lived in the room and how it may or may not have influenced my response to confinement.

This approach is influenced to some degree by the work of architect Sarah Wigglesworth, who has used the concept of ‘activity mapping’ in analysing how a domestic dining table might be used over the course of an evening and what this might mean for the design of a house and how a designer might approach it. In her paper ‘The Disorder of the Dining Table’ (Wigglesworth 2022), she states the following:

‘Accepting the accidents, embracing the unexpected and learning to admire ‘the dirt’ that results, is part of acknowledging that life isn’t always as we expected; and this challenges our ability, as architects, to predict and manage the realities of lived experience.’

Applying this thinking to an auto-ethnographic account of my occupation of a space begins to suggest a number of techniques to analyse this and to inform the development of the study methodology.

I was isolated in a bedroom for three weeks in order to receive an allogeneic stem-cell transplant. The room had not been originally designed to be an isolation facility, being within a 50-year-old hospital where provision of some of the core isolation features were difficult to achieve.



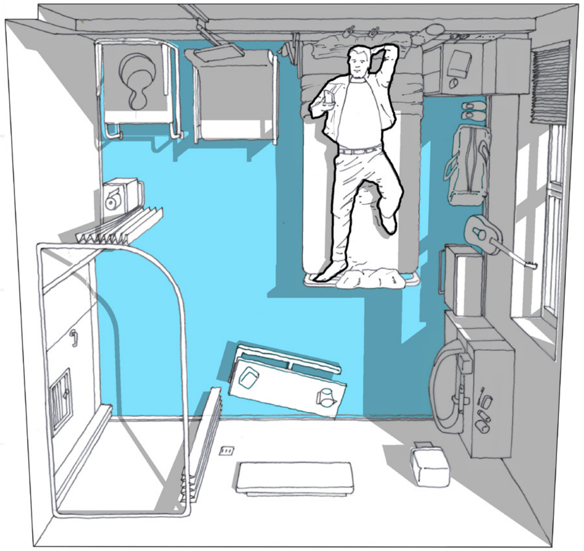
1. My inpatient isolation room

My room did not have a lobby to separate it from the adjacent circulation corridor and create a pressure differential. It did not have an ensuite shower/bathroom.

The room was approximately 16sq.m in area and contained a bed, chair, storage unit and wall-mounted TV.

It also contained a commode and a wash hand basin. A cubicle curtain arrangement allowed some privacy should the room door be opened during any personal/private activities.

Windows were sealed shut.

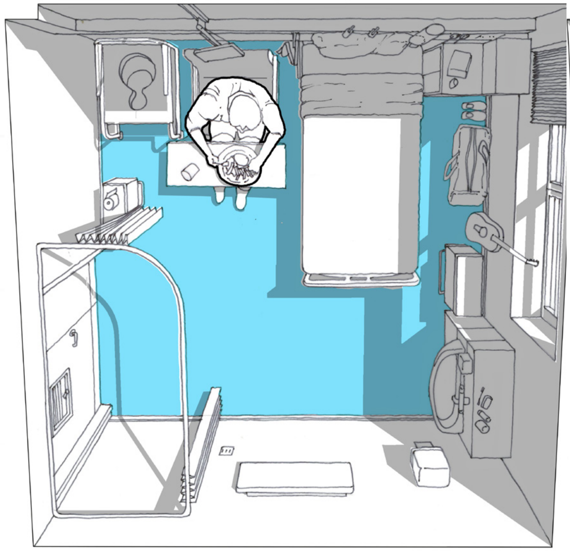


2. Stuff!

I had been warned that I might be kept in isolation for several weeks and was encouraged to bring personal items to keep me active and alleviate boredom.

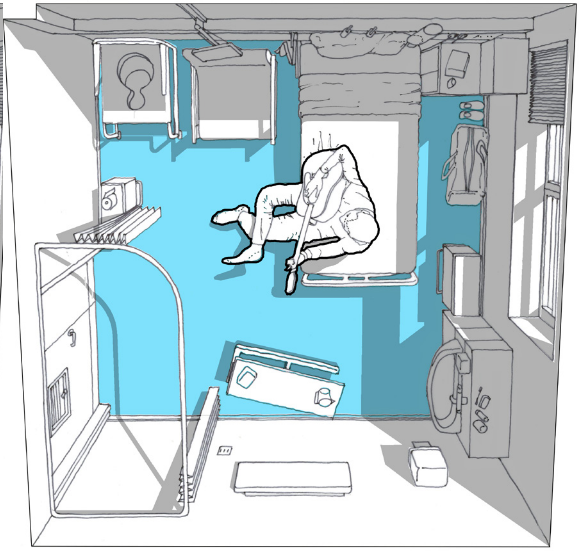
So as well as mobile phone and tablet I also had a lap-top, a guitar, a small amp and effects board. I also had several books plus holdalls and soft blankets. Clothes, slippers, trainers, flip-flops.

I had a lot of ‘stuff’ but there wasn’t much space for it to be stored. I was constantly moving items around to maintain space for staff to circulate in the room.



3. Eating

Setting aside the quality and choice of the food being offered, having to eat it adjacent to a commode was not particularly pleasant. The treatment effects instilled a constant level of queasiness. The sealed window limited the possibility for the smell of cooked food and other odours to be expelled quickly.

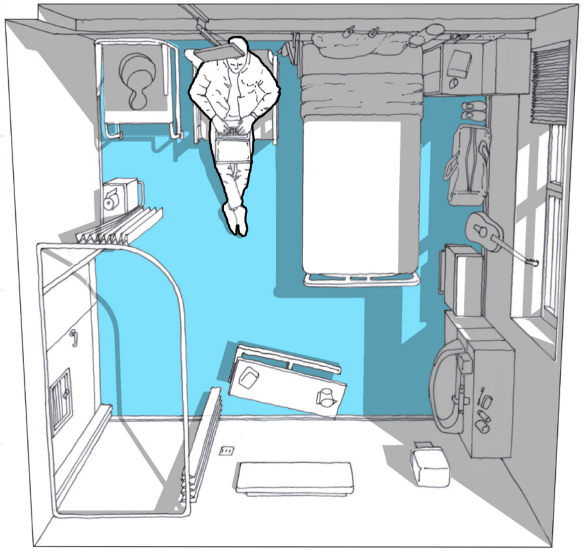


4. Boredom

Hour after hour, day after day, time often dragged. Meals, often a ‘landmark’ to break down the day, were sadly not something to look forward to. How to create routine became a daily challenge in the fight to ignore the deepest feelings.

I was warned about boredom so took in my guitar. This helped but there was insufficient space for it to be stored. How much thought had gone into occupant activity I pondered? Why shouldn’t someone bring in a key-board, or a static bike? Was there space for a prayer-mat if the occupant desired?

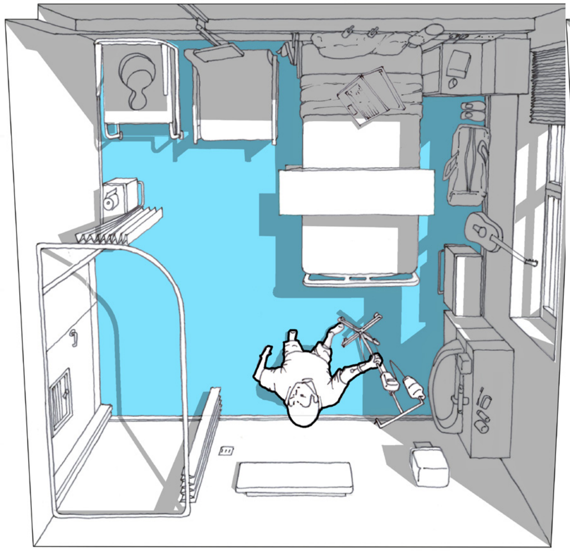
Eating became an ordeal – I lost weight and needed naso-gastric tube feeding for part of my admission.



5. Work

I took my lap-top with me as another tool to counteract boredom. There were times when I felt too unwell to face work but I managed to progress some practice work and even submitted a planning application whilst admitted. Thankfully, wi-fi access was good.

A desk, table or some space to sit and work comfortably would have been welcome but as always the bed dominates. This space should be seen as much more than a ‘bedroom’!

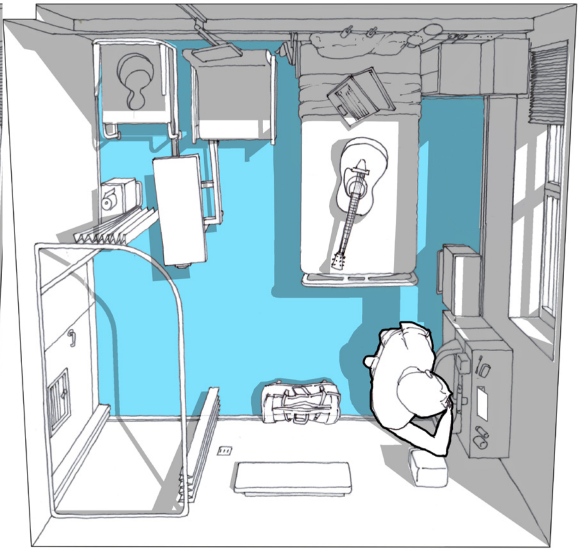


6. Movement

Moving around the room was not easy – furniture and my personal effects made an already small room even more difficult to navigate.

Being connected to an IV infusion pump on a mobile drip-stand was particularly difficult. On several occasions the line became caught on furniture and pulled out of my arm.

The need to then request nursing assistance to deal with bleeding and discharge on the floor added unnecessary work for staff. I felt guilt and frustration at needing to divert them from their routine tasks.

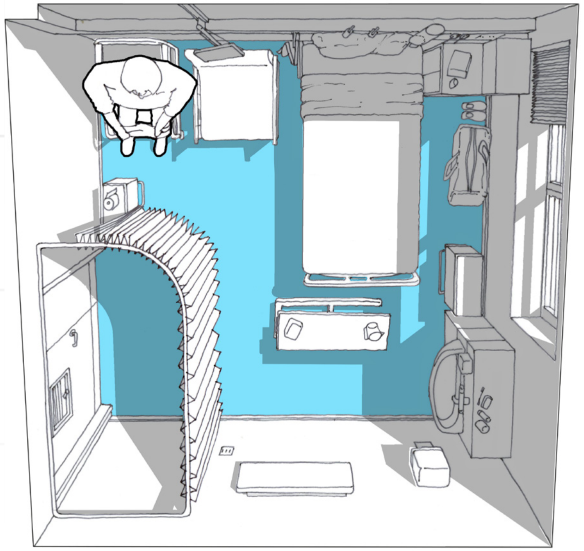


7. Ablutions

I had no access to a shower, for three weeks. Washing and shaving at a small sink was the only way. There was no mirror, presumably given possible health & safety risks of breakage.

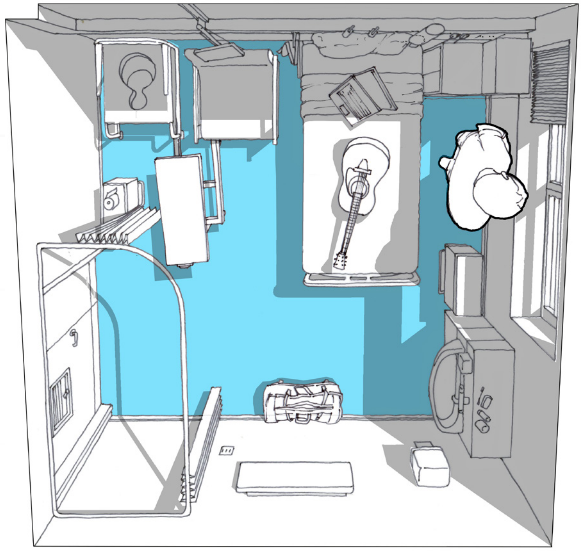
A curtain track in front of the door offered some privacy during intimate washing – occasionally I forgot this and staff sometimes entered with unfortunate timing!

Eating became an ordeal – I lost weight and needed naso-gastric tube feeding for part of my admission.



8. Going to the toilet
No shower and no access to a bathroom with a separate toilet. A commode was deemed adequate – 'just press the nurse-call buzzer and someone will be along quickly to take away the bowl.' This was rarely the case in reality. Sealed windows prevented any rapid odour release. No amount of Lynx Africa could mask the smell.

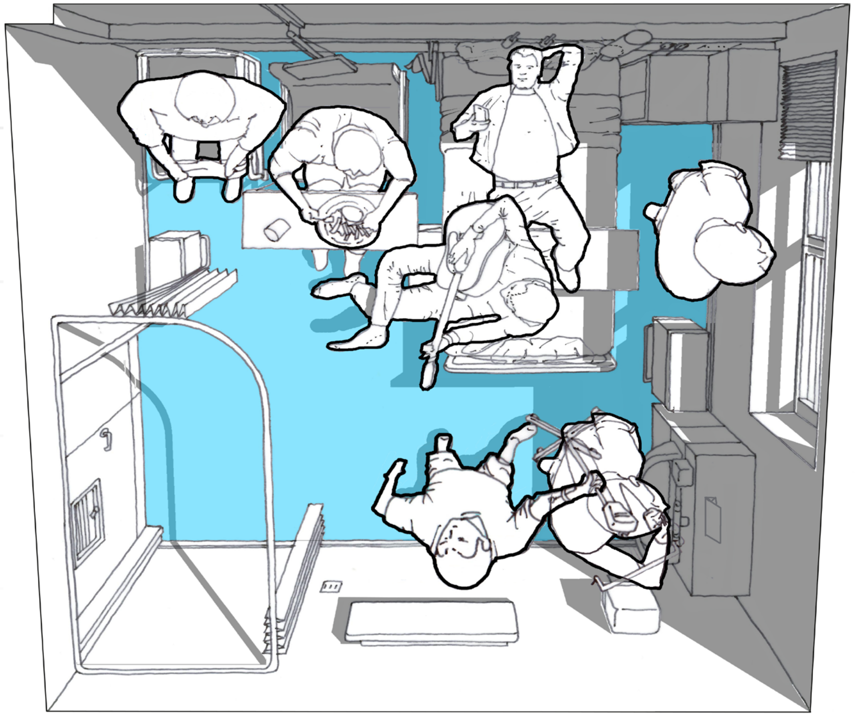
Quite often, the food trolly would arrive within just minutes after.



9. Staring out the window
Unsurprisingly, there were many moments when I could barely tolerate things. Being forced to live like this did feel like a punishment at times.

Staring out of the window for long periods became a frequent response. The treatment was the priority and it was my job to try to get better but it felt as if the poor environment was an unnecessary hurdle to get over. I hated not having a bathroom or a toilet obviously but I also yearned for more space, some access to the outdoors and time away from the bed.

'You gotta stay in to get out' became a mantra for me in the constant push to tolerate and endure.



An exercise in overlaying all the various activities
Personal items, equipment and furniture provides an interesting analysis of the space, something which I had never done in normal design practice before and had not seen evidence of anyone else adopting this method either.

Much effort and time is often spent in locating all fittings and furniture within a space, as part of the traditional detail design process in healthcare. The focus is on ergonomic fit and functional space and yet analysis of activity, movement and use of space is rarely considered.

This is surprising and disappointing, especially in the context of repeatability where prototyping and optimisation should figure more highly in settling upon finalised layouts. Yet again, the patient voice (the way they behave, the things they use, the space that they need) is diminished in the face of function and clinical efficiency.

7 Participant feedback, early findings

7.1 Background

Using my experience as both a design practitioner and a patient allows me to undertake a bilateral approach to enquiry. In engaging with potential study participants I am able to adopt two useful but different perspectives: the viewpoint as an architect and the viewpoint as a patient. I am therefore able to change the focus of my questioning to obtain feedback which might vary in its focus from either the traditionally architectural to the more emotive and experiential.

Whilst the work undertaken to date in this study has not yet fully engaged with participant recruitment and interview, the design of the study protocols and recruitment methods have already benefited from public and patient input. This is something that is heavily emphasised as an essential part of the ethical approval process. So even at this relatively early stage it is possible to identify some patterns and trends through early engagement with colleagues and contacts. Liaison with some former patient contacts, colleagues and a clinician on a ‘pilot basis’ about the study has presented some initial feedback obtained through conversations with an underlying approach of either ‘Jamie the Architect talks to’ or ‘Jamie the Patient talks to’. Remembering the advantages that a more auto-ethnographic aspect can bring to the study, this has even included a session where I interview myself (as architect talking to patient or vice-versa). The initial results are summarised as follows:

7.2 The patient viewpoint

7.2.1 Jamie the architect talks to patient one

Engagement with a school of architecture colleague who is also a former patient with experience of stem-cell transplantation has been extremely useful. An added dimension was his experience of an ambulatory care treatment approach to the transplant process (indeed he was the first patient in Wales to undergo this treatment option). As well as recollection of some negative aspects about the inpatient environment (including excessive noise) his input has allowed comparative considerations of the benefits and challenges involved with either wholly inpatient care versus an ambulatory approach with an element of care-at-home.

7.2.2 Jamie the patient talks to patient one

Speaking to Patient 1 as a former patient myself alerted me to an important consideration for future interviews. It served as a reminder to adopt a sensitive approach and to remain agile in dealing with unexpected feedback. Here, it transpired that Patient 1 was due to return to hospital for further treatment – something I was unaware of prior to the conversation. An initial approach which assumed that stories of the ‘horrors’ of time in isolation could be shared had to be quickly changed during the conversation recognising that he was due to repeat the experience in the same location. I quickly needed to recognise that he may not wish to be reminded of the upcoming treatment challenges and to alter my questioning accordingly. A useful lesson in the need to be able to ‘pivot’ the conversation without warning, therefore.

7.2.3 Jamie the architect talks to patient two

Patient 2 was a personal contact from my own period of hospitalisation - a former patient who had also received a stem-cell transplant at UHW, Cardiff. Architectural questioning within our conversation quickly identified the lack of space within the room as a key factor. Recognising that there were periods of relative wellness during the isolation process, the ability to undertake some exercise in the room, perhaps using a treadmill or stationary bicycle, was not possible given spatial constraints. There was also a shared desire for better natural ventilation for odour release, especially as a means to address sensitivity to odours from cooked food – often a source of queasiness leading to meal times becoming an ordeal and ultimately forcing the need for naso-gastric feeding.

7.2.4 Jamie the patient talks to patient two

Despite the hardship of enduring isolation, Patient 2 managed to adopt a more positive approach. ‘Getting better was my job’ was how he saw his role in the process. Learning this feedback was useful in understanding that patients may not all succumb to the mental challenges of confinement – something to be mindful of when the full process of interviewing commences.

7.2.5 The staff viewpoint

The study continues to benefit from not only academic supervisor input but also guidance and feedback from clinical supervisors. It has therefore made sense to liaise with one of my clinical supervisor team on a ‘pilot’ basis to rehearse some key issues prior to formally engaging with clinical staff at each of the three proposed centres.

7.2.6 Jamie the architect talks to a clinician

An important query for this study is to properly understand the physiological response to treatment during the transplant process and to consider what this means for the quality of the space and the influence this may have on the outcome. Here, it was confirmed that whilst there are always some exceptions, the majority of isolated patients undergoing an allogeneic transplant do not present as ‘unwell’ for the entire period. There are periods during the preparatory, treatment and recovery process when patients feel reasonably well. This places an extra pressure on the quality of the isolation room environment to perform as well as possible. Perhaps it could be said that if the occupant is unwell and mostly bed-ridden then matters relating to space and room activity are of lesser importance whether isolated or not. But if the patient feels relatively fit, then the need for the room to lessen the effects of confinement surely becomes more important. A critical factor to consider therefore and usefully clarified through access to a more clinical viewpoint.

7.2.7 Jamie the patient talks to a clinician

Being mindful of inevitable counter arguments against enhanced spaces for isolation practices (based on an avoidance of additional capital costs), it is useful to obtain some clinical endorsement of the idea that improved facilities provide real value if well-being can be improved. Here, the clinician confirms that a patient with a better sense of well-being and a positive outlook (which may have been enhanced through provision of a more comfortable environment) is more likely to engage, will recover quicker and be far less likely to need extensive and expensive follow-up services and rehabilitation. Conversely, the clinician confirmed that a patient struggling with the effects of confinement, made worse by a poor isolation room environment, would be more likely to remain in bed for extended periods and suffer issues like muscle wasting and other knock-on effects which would increase the need for additional post-transplant care. It was good to hear therefore that there were real benefits to the overall clinical service in terms of cost-reduction through the provision of enhanced isolation environments. Providing a better and ‘nicer’ room was more than just a luxury– it offered real long term benefits to the patient, nursing and clinical staff and the service as a whole.

8 Discussion

This paper summarises an interim position. The wider study continues yet the work done to date is extremely useful in establishing an initial position – much has been learned already.

Firstly, the process of obtaining ethical approval rightly places an emphasis on early engagement with patients and other members of the public to inform study protocols and design. Performing early 'pilot' interviews and discussion with contacts and colleagues has already shown a pattern of themes emerging. Even at an early stage, concerns regarding space, noise, ventilation and promotion of 'wellness' are shared and endorse my own patient experience, highlighting the value of an auto-ethnographic lens through which to channel the emerging narrative.Already, some core issues and observations can be identified, warranting further investigation.

It is clear that current NHS design guidance about isolation facilities pays too little regard to the occupant experience or the challenges of confinement. There is little evidence that the design of these spaces, even in contemporary examples, are influenced by the complex needs of an isolated occupant. For too long the emphasis, based on application of guidance, has been about the design of 'the box' and its technical performance with not enough attention paid to the daily activities that take place within it. Too much attention is focussed on the bed and the space for treatment activities around it rather than a wider consideration of the daily movements and activities of the occupant.

The advent of the government's 'New Hospital Programme' (Care 2025), which unsurprisingly favours standardisation and repeatability, does not yet include a meaningful assessment about what the isolation room needs to be. The opportunity for true prototyping and optimisation in support of an improved facility has not yet been taken up – the approach of taking a standard inpatient bedroom and simply adding a lobby for PPE-donning and pressure differentials continues. Surely, for such an important national healthcare delivery initiative the chance to develop a more patient-focussed solution for this special room-type is clear, especially given the potential benefits to users (both patients and staff) and the wider service. The clinical view, which says that improved patient well-being, through provision of better spaces, has a direct impact on positive outcomes, must surely be worth some additional capital investment.

So how can designers support the aim to better cater for the needs of the isolated inpatient? The focus on compliance with government design guidance needs to change to include recognition of experiential factors. Engagement with patient advocates needs to figure more highly in stakeholder engagement initiatives. Also, space needs to be made available within the traditional design process to allow and encourage the designer to spend time contemplating the occupant and how he/she lives within the space.

Given the unique experiential factors that the isolation facility must recognise it is perhaps more appropriate to think in terms of 'place' rather than 'room' when one embarks on the design process. An initial mapping exercise of my own time spent in isolation already illustrates some aspects which should be more informative in developing concepts and solutions. It is interesting to consider the tools and processes employed by urban designers when conceiving a quality 'place'. Consideration and mapping of movement, activity, scale, orientation, use-class etc., often contributes to ideas which allow successful places to be created. Surely, for a place such as an isolation facility, with the daily challenges faced by the patient, a design approach which adopts a similarly forensic analysis of occupant behaviour and spatial need can only be a good thing. The brutal nature of isolation needs to happen in as nice a 'place' as possible so that its effects are minimised.

The relationship between humans and their surroundings is perhaps no more polarised than in a setting such as an isolation room. It could be said that there is perhaps a moral imperative for the design of these rooms to be given the highest priority. The occupant not only has to endure arduous physical treatment effects, where outcomes are uncertain, but must do this in the most challenging of emotional circumstances. Being alone with one's thoughts and fears in a space from where there is no release places an enormous responsibility on those who design such spaces. The focus must be re-directed from object and process to the person. The designer must therefore begin to consider not only the technical, ergonomic, material and aesthetic realms but also those linked to occupant behaviour. As well as understanding what is done to the person in the room, thinking also needs to switch to what does the occupant do, in what part of the room, when and using what items. This is especially important when one thinks deeply about remaining in a single space for not hours, or days but weeks.

True appreciation for the challenge faced by a confined patient might unlock the potential for the isolation room to be not only a container for treatment activities but also a tool which can play an active role in boosting wellness and recovery. The initial engagement afforded so far allows this study to continue with new motivation to hear the occupant voice with more depth and clarity.

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