Journal of Mental Health Training, Education and Pr

Co-Developing a Care Pathway for Patients Discharged from Inpatient Treatment for Anorexia Nervosa: A Case Study

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18th March 2024

Dear editors,

Thank you for your consideration of our paper – ("Co-Developing a Care Pathway for Patients Discharged from Inpatient Treatment for Anorexia Nervosa: A Case Study") – and for the thoughtful and constructive reviewer comments we have received. We are particularly grateful that the reviewer has highlighted the merits of our paper (as an applicable piece of co-development work in a real-work NHS context), whilst giving critical feedback that it does not conform to the methodological standards as a piece of research, a criticism we accept.

In response to reviewer feedback, we have re-drafted the paper as a case-study, in line with The Journal of Mental Health Training, Education and Practice's definition. We are keen for this work to be publicly available to enable other health services to engage with our approach, but agree that a case-study is a more appropriate framing for the co-production and participatory methods we utilized in this paper.

We feel there was confusion around the aims of the piece, and we have clarified these to make it clear what we sought to accomplish with this piece of work, as well as re-writing the introduction to add more context to our approach.

Please find a detailed response to reviewer comments below. We look forward to hearing from you.

Best wishes,

Daniella Mallory and co-authors

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General Feedback	
Overall this is an interesting and highly applicable piece of quality improvement. The clear integration of lived experience and thoughtfulness around the development of service structure has to be commended. However, I am concerned about this being presented as a piece of research and whether the underlying aims of the paper are robustly met. As it currently stands I would not recommend this for publication based on these concerns but this should not detract from the excellent QI and participatory research processes that have taken place here. 1. **Originality**: This paper is commendable for its clear use of participatory methods to	We appreciate your positive feedback on our paper, particularly in your appraisal of its merits as a piece of participatory/co-produced service development, whilst drawing attention to the fact that it does not meet the standards for a robust piece of research. We agree that there are significant limitations to this work and that framing it predominantly as a qualitative research paper (forming Phase two of a larger process of service development) is inappropriate given key methodological issues such as the small number of patient participants we sampled. We have instead chosen to re-draft it as a 'Case Study', and request that the Journal of Mental Health Training, Education and Practice publish

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improve the quality of service delivery. However, if considered as a robust research paper there is methodological problems. 5. **Practicality and/or Research implications.** This is a strength of the paper, with this being very practically focused and an great piece of quality improvement involving lived experience My concerns is its robustness to be considered a research study and meeting the underlying objectives of the paper.	it as such. We are grateful to the reviewer for highlighting its applicability, practical focus, the thoughtfulness and interestingness of this work and the quality of our participatory research processes. As such, it fits under the journal's definition of a 'Case Study' – reporting on "actual interventions or experiences within organizations. It can be subjective and doesn't generally report on research." We believe that a "case-study" is a more accurate description of the intervention-development processes that occurred during this work, and hope that other services would be able to benefit from understanding and building on these. We have made key following changes as a result including to the title of the paper (*Co-Developing a Care Pathway for Patients Discharged from Inpatient Treatment for Anorexia Nervosa: A Case Study),* abstract, methods, and discussion to emphasize the co-production element and intervention development, re-framing the qualitative work as a "nested qualitative component" within the case-study, with figures also being updated to reflect this change. See below for discussion of research aims/objectives.
6. Quality of Communication: Does the paper clearly express its case, measured against the technical language of the field and the expected knowledge of the journal's readership? Has attention been paid to the clarity of expression and readability, such as sentence structure, jargon use, acronyms, etc.: Yes, genenrally well written	Thank you, we also have refined the paper to improve clarity of expression.
Introduction	
I am slightly concerned about the structure of the paper, while I do think there is a need to clearly detail the commendable QI process and phase 1, I do think that this means that some of the crucial experience of IP literature has been omitted from the introduction/rationale. I think it would be strengthened if this could be incorporated into the intro instead while retaining the face that phase 1 include this review of the literature.	We have amended the introduction to incorporate some of the literature on qualitative experiences of inpatient care and transition – tying it to our central aims of understanding patient needs during this process. This is included under the subheading "Developing Targeted Interventions."

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Introduction: At times there are quite strong statements made in the introduction which do need qualified or changed. e.g. The statement that "incidence of anorexia in the UK has increased over the past 30 years" needs to be qualified with a citation, and also consideration needs to be made that the general consensus is that this is due to increased capacity to accurately assess and identify rather than a true increase in incidence.	All these statements have either been removed (as with the example given), had appropriate citations added, or further qualification has been provided. Since the focus is on understanding experiences of inpatient transition, many of the background statements on eating disorders have been removed (including this one), to allow more space for this focus.
The Ayton (2022) reference is really only considering COVID related increase in service demand, therefore this sentence needs to be adapted accordingly as is not aligned with the statement of a 30 year increase.	We agree, and have removed this statement as it was not necessary for our argument.
The statement about SEDU's supporting weight gain but not similar psychological improvements at discharge also needs to be qualified with a citation as the next sentence is more in relation to relapse rather than supporting this statement. The next sentence stating that relapse may occur following discharge as patents are often not weight restored in in contrast and conflict with this sentence above?	We have removed the second part of this statement, about pathology not changing post-discharge, and instead changed it to how any weight gain often does not last after discharge, which is more reflective of the literature cited.
2. Relationship to Literature: Does the paper demonstrate an adequate understanding of the relevant literature in the field and cite an appropriate range of literature sources? Is any significant work ignored?: I do have concerns about a lack of citations in some quite leading statements in the introduction and it struck me that there was an absence of robust critical evaluation of the previous qualitative literature of the experience of inpatient admission, despite a systematic review of the literature having taken place	We have amended the introduction accordingly, see above, and have highlighted the importance of understanding the qualitative literature on patient experiences of IP ED care and transition to developing targeted support for them during this time.
Study Aims	
Methodology - while the paper quotes 8 participants as being an acceptable sample size for a small qualitative study, the first aim of this study appears to be to understand the experience of IP treatment. with only 3 of the 8 participants being patients, this is not an appropriate sample size to meet this aim. I am struggling therefore with the integration of both groups (patents and clincians) in development of themes many of which are reflections on inpatient experience	Thank you for highlighting that some additional clarification on study aims is needed. On a close re-reading of the paper additional ambiguities in wording emerge where it seems like only patient interviews contributed to some themes (where actually it was both staff and patients' perceptions of what patients needs were on leaving IP), as well as confusion over where the aim of understanding staff and patient experiences of patient transition fitted into our broader aim of developing our pathway.

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e.g. emphasis on BMI, when there is not enough participants to be confident that this is a robust theme. This paper would have been stronger if instead it reported solely on the reflections of the discharge process. 3. Methodology: Is the paper's argument built on an appropriate base of theory, concepts, or other ideas? Has the research or equivalent intellectual work on which the paper is based been well designed? Are the methods employed appropriate?: Methodologically I have concerns about the very small number of patients participating in the qualitative study, despite a major aim of this paper being to understand the patient experience of intent admissions. This does not feel adequate to fuller example this research aim. 4. Results. Yes, they are presented but the double research question of experience and reflections on discharge pathway is confusing here.	We have clarified the aims to reflect the focus of our work: *"The overarching aim of this case-study is to utilize co-production methods to develop a novel discharge pathway that meets the needs of patients leaving inpatient care.* *The nested qualitative component within this study has the following research objectives:* *1) To explore clinician and patient perspectives on what support is needed for patients transitioning from IP to OP ED care.* *2) To provide a preliminary evaluation of the acceptability of the co-developed proposed pathway structure, and any recommendations for changing the pathway to meet these needs."* The discussion section of the paper provides an important demonstration of the ways in which the first objective leads to the second objective – many of the changes made to the pathway were as result of understanding difficult patient experiences of IP care and transition, enabling us to tailor the pathway to meet these (examples of which are given in the discussion.) We would argue that the dual objectives of the nested qualitative component are key to this case-study, and interviewing participants about their perceptions of the IP care and the transition process, before asking them to comment on the pathway enabled a richer level of understanding, and an increased willingness to make suggestions for adapting the pathway than we would have gained simply by presenting the pathway components. Throughout the paper we have changed the wording from "patient experiences" to clinician and patient perspectives on patient needs, as this reflects our aims and approach in analysing the qualitative data, and our study findings. We hope that this makes the integration between the "double research question" clearer, the integration of staff and patient perspectives, and resolves some of the understandable apprehension about the small sample size for patients – the interviews focus was on understanding what patients needed

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	during the transition period (according to both clinicians and patients interviewed) as well as how the pathway could be better adapted to meet these needs. We have a paragraph added to our methodology section (under participants and recruitment) to explain and justify the integration of staff and patient perspectives in this work. Ultimately, this was a piece of work designed to improve and develop a necessary pathway in our service, and whilst the qualitative component might not adhere to the highest standards of robustness (given the small sample size) we were constrained by limited time in which to do this work (something we reflect on in the discussion section.) We believe that by reframing it as a case study (as well as clarifying the aims of this work), we have resolved the issues raised by this reviewer.

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Co-Developing a Care Pathway for Patients Discharged from Inpatient Treatment for Anorexia Nervosa:

~~Clinician and Patient Perspectives~~ A Case S~~s~~tudy

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Abstract

Purpose: The transition period from eating disorder inpatient care to outpatient care can be difficult for patients and is often characterised by high relapse rates. The ~~purpose~~ aim of this study was to co-develop a novel treatment pathway to support patients during this critical period. ~~gain a greater understanding of both patient and clinician experiences of inpatient treatment and the transition from inpatient to community care. The case study aimed to understand what could be helpful in a discharge pathway for these patients and use this to develop a novel treatment pathway. , to develop a novel treatment pathway to support these patients during this critical period.~~

~~Design/methodology/A~~approach: This was a ~~mixed- methods~~mixed-methods case-study utilizing co-production methodology and a nested qualitative component ~~study utilising participatory methods such as co-production methodology~~. We co-ddeveloped an initial proposed pathway structure with clinicians and people with lived experience of an eating disorder, based on a review of the literature. ~~,~~We then conducted interviews -with ~~followed by interviews with~~ clinicians and patients (n=8) to refine the pathway; these were analysed using framework analysis.

Findings: A four component pathway structure was developed. Six main themes emerged ~~following~~ from our qualitative analysis: autonomy, the need for holistic patient care, difficult experiences, service provision, ~~relationships~~relationships, and feedback on the discharge pathway. ~~Findings suggested that although IP treatment is an important part of recovery for some patients, it can be difficult due to feelings of powerlessness and the emphasis put on weight gain.~~

Originality/value: ~~Co- production was~~Co-production approaches were used to develop the inpatient discharge pathway with members of ~~the~~ a Lived Experience Advisory Panel (LEAP) alongside clinicians. This study was also the first intervention development study ~~to~~ aimed at providing targeted support for patients dealing with the adverse effects of hospitalisation, and difficulties transitioning to outpatient care.

Practical implications: This study highlighted the importance of centring patient autonomy during treatment, as well as ensuring treatments are holistic in nature. This may reduce the

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high levels of relapse associated with discharge from inpatient treatment and improve the quality and effectiveness of eating disorder treatment delivered.

Introduction

Clinical Context.

Anorexia Nervosa (AN) is an eating disorder (ED) characterised by an intense fear of gaining weight, resulting in the restriction of nutritional intake or persistent behaviours to interfere with weight gain. This leads to low body weight as well as a preoccupation with food and body image concerns (5th ed.; DSM-5; American Psychiatric Association, 2013). In the UK, ~~incidences of AN have increased over the past 30 years with~~ studies report ~~reporting~~ a lifetime prevalence rate between 2-4% (Keski-Rahkonen and Mustelin, 2016). ~~Referrals for adult specialist eating disorder units have increased since the Covid-19 pandemic, leading to an increase in service demand (Ayton *et al*, 2022).~~ Due to the life-threatening complications of AN, EDs have the highest mortality rate amongst all psychiatric disorders (Arcelus *et al*, 2011). A range of interventions are used in the treatment of AN, however there is a consensus that most patients should be treated in an outpatient (OP) setting unless their physical or mental health is significantly compromised (NICE, 2017). OP treatment for AN has been cited to be more cost effective (Striegel-Moore *et al*, 2000) and importantly has been associated with better patient outcomes, whilst also preserving patients' autonomy, and their overall acceptability of the treatment (Hay *et al*, 2019).

Of those receiving OP care, studies have shown that 20-30% of patients will not respond to treatment and will subsequently require more intensive support either in an inpatient (IP) or day-patient (DP) care setting (Ambwani *et al*, 2017). Research has suggested that it is the intensity of treatment in IP units, for example supervised meals and frequent monitoring, which facilitates rapid change and leads to faster weight gain (Hartmann *et al*, 2011).

Transition from IP to OP. Although IP treatment is often crucial in managing medical risks associated with low body weight, studies have shown that physical improvements such as weight gain and restored physical health functioning obtained on a SEDU (specialised eating disorder unit) do not persist~~s~~ post discharge~~.~~ ~~do not result in similar psychological improvements following discharge~~. For example, a systematic review reported that 31% of patients relapse following discharge from a SEDU (Berends *et al*, 2018) with some becoming caught in a 'revolving door', experiencing multiple readmissions. Relapse may occur following discharge as patients are often discharged before full weight restoration has occurred and whilst patients are still expressing high disorder pathology leading to higher rates of readmission in patients with a low body weight at discharge (Redgrave *et al*, 2021). Support following discharge is crucial to prevent readmission; NICE guidelines recommend that patients discharged from IP care should be followed up for at least 1-year post discharge to support the transition into community care (NICE, 2017).

Some services offer DP care following an IP admission with the intention of facilitating a smoother transition. DP treatment offers less intensive treatment and aims to encourage greater independence which can improve patient outcomes at follow up (Brown *et al*, 2018). Despite the benefits of DP treatment, less than half of NHS ED treatment providers offer a DP or intensive home treatment service (BEAT, 2019).

Where adequate support after an IP admission is not available, it can be difficult for patients to maintain and transfer therapeutic gains made whilst on an IP unit (Byran et al, 2022).

Developing Targeted Interventions. To bridge this gap between IP and OP care, a variety of interventions have been piloted in OP treatment teams to address the difficulties patients

face following discharge. This includes skills-based programmes for patients and carers which aim to develop patients' autonomy (Neumayr *et al*, 2019) in addition to smartphone guided interventions to support symptom stabilisation following IP treatment (Tan *et al*, 2010). These feasibility trials have demonstrated positive findings which is encouraging for OP services where a DP service is not feasible.

Understanding patient needs during this transition period is key to developing better targeted interventions which can support patients and prevent relapse.

A systematic review of people's lived experiences of inpatient treatment highlighted the "complex and multifaceted nature" of IP treatment (Rankin *et al*, 2023), with patients being constituted as powerless in their own treatment, aligning with other qualitative research indicating that IP admissions can be experienced as coercive, distressing, or traumatic for some patients (Eli *et al*, 2014; Mac Donald *et al*, 2023). It is therefore unsurprising that qualitative studies have also found transition period difficult for patients, who can experience difficulties living eating autonomously after receiving intensive support during their admission (Cockell *et al*, 2004; Smith *et al*, 2016) as well as experiencing issues with continuity of care, a sense of ambivalence about recovery, and the need for more transition support both from professionals and social networks (Clark Bryan *et al*, 2022; Pagano *et al*, 2023). ~~Qualitative studies have found that patients experience difficulties eating autonomously after receiving intensive meal support during their admission (Cockell *et al*, 2004). Other studies have reported that patients feel unprepared for life outside of hospital, resulting in pervasive feelings of loneliness upon returning home after admission (Cardi *et al*, 2017).~~

~~To bridge this gap between IP and OP care, a variety of interventions have been piloted in OP treatment teams to address the difficulties patients face following discharge. This includes~~

~~skills-based programmes for patients and carers which aim to develop patients' autonomy (Neumayr *et al*, 2019) in addition to smartphone guided interventions to support symptom stabilisation following IP treatment (Tan *et al,* 2010). These feasibility trials have demonstrated positive findings which is encouraging for OP services where a DP service is not feasible. Some research indicates that IP admissions can be experienced as coercive and distressing for some patients (Skivington *et al*, 2021) however no evaluations exist of interventions to support patients after this form of iatrogenic harm.~~

This research indicates the diversity of patient needs during the transition, including a space to process difficult experiences of IP care, consistent relationships with clinical staff during this period and support to regain autonomy and ownership over their recovery.

~~In the absence of DP service, there is a need for alternative treatment options during this vulnerable period to minimise the number of patients who relapse.~~

Study Context and Aims. To address a clear gap which often lies in community treatment provision, the Sussex Eating Disorder Service (SEDS) and SPIRED research clinic have co-developed a discharge pathway, informed by a review of the existing literature and ~~-~~by patient and staff perceptions of patient needs during the transition period~~-patient experiences of transition, and a review of the existing literature~~. ~~The pathway, in addition to offering more intensive support to patients, aims to address and acknowledge experiences encountered during an IP admission.~~ This ~~qualitative~~ ~~paper~~study ~~will form phase two of the~~reports on the first two phases of intervention~~-~~-development ~~process~~ for this discharge pathway, outlined in F~~f~~igure 1. We utilized a case-study approach - to allow a more in-depth exploration of the process we took in developing a novel pathway within a "real-life [healthcare] setting" (Crowe *et al,* 2011) and enable us to work in a more methodologically flexible way to meet service needs with this project (Hyett *et al,* 2014).

The overarching aim of this ~~present~~ case-study is to utilize co-production methods to develop a novel discharge pathway that meets the needs of patients leaving inpatient care.

The nested qualitative component within this study has the following research objectives:

1) To explore clinician and patient perspectives on what support is needed for patients transitioning from IP to OP ED care.

~~1) understand the experiences of patients leaving inpatient care, in order to develop and refine a care pathway that is able to meet their needs.what would be helpful in a discharge pathway for patients leaving inpatient care. The study has the following research objectives:~~

~~2)~~

~~3) Understand patients' experience of IP treatment, including any factors affecting patients' experience of transition from IP to OP ED care.~~

~~4)~~ To pProvide a preliminary evaluation of the acceptability ~~of a novel discharge pathway designed to target the needs of individuals as they transition from IP to OP care.~~of the co-developed proposed pathway structure, and any recommendations for changing the pathway to meet these needs.

~~5)~~2)

Methods

~~This~~ In this ~~Quality Improvement (QI)~~case-study we ~~project~~ utilised co-production methodology to develop and refine a novel treatment pathway. This project was divided into three phases, all of which contributed to an iterative intervention development process of a discharge pathway for patients who have been discharged from a SEDU. The three phases of the intervention development process are described below in Figure 1. The present study

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focuses on phases one and two, phase three is currently ongoing within our service. During phase 1 we conducted scoping searches, and co-development workshops to develop an initial proposed pathway structure. A nested qualitative study (phase 2) offered a preliminary evaluation of this pathway, and, through understanding patient needs in this critical period, recommendations for developing this pathway.

~~a mixed- methods case study methodology with participatory methods throughout such approach as well as emphasising co- production throughout. This project was divided into three phases, all of which contributed to an iterative intervention development process of a discharge pathway for patients who have been discharged from a SEDU. The three phases of the intervention development process are described below in figure 1. Although the present study largely focused on phase two, phase one of this process, which has already been completed, has been described in addition to phase three which will commence following completion of the present study.~~

Figure 1: *The intervention co-development process*

[Insert Figure 1]

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This study adhered to the Medical Research Council's (MRC's) guidelines for developing complex interventions which states that complex interventions should be based upon evidence and theory whilst also acknowledging the experiences of stakeholders as significant (Smith *et al*, 2016).

Phase 1: Initial intervention co-development

Scoping searches. The first phase of this ~~QI project~~case-study involved conducting scoping searches of the literature to identify ~~how patients experience IP treatment in addition to understanding patients'~~ key factors which could affect patient experiences of transitioning from IP to OP care, including any difficult or traumatic experiences during IP treatment, which might need addressing in post-discharge support. ~~.~~The authors accessed the following databases: Google Scholar (accessed from England, UK) and University of Sussex Library databases (including Medline, JSTOR, PsychINFO, PsycArticles, PubMed and Wiley Online Library.) Key search terms were 'inpatient', 'eating disorder', 'eating disorder unit', 'discharge', and 'transition'. Exploration of the literature revealed important themes about IP treatment, including how patients felt as though they were not seen beyond their ED (Smith *et al*, 2016) as well as experiences of coercion and feeling unprepared to tackle their AN after treatment (Offord *et al*, 2006). The research highlighted the need for an appropriate discharge intervention following discharge from an IP unit as well as a need for an intervention that acknowledges patients' differing experiences of admission. These findings were used to inform the co-development of the discharge pathway, and the topic guides for the nested qualitative component (phase 2).~~.~~

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Focus groups. The discharge pathway was co-produced by clinicians and researchers at SEDS during focus groups which ran from March 2021 to March 2022. A total of twenty clinicians attended over the course of twelve focus groups. In addition, a Lived Experience Advisory Panel (LEAP) comprised of seven experts with direct experience of Eds provided feedback regarding the discharge pathway, to ensure that it was relevant and acceptable for the intended patient group. All discussions were recorded by a member of the SPIRED team and circulated to attendees of the focus groups. The proposed discharge pathway is described below in Figure 2.

Figure 2: *The Discharge Pathway*

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Phase 2: Nested Qualitative Study: ~~The Present Study-~~ Refinement and Preliminary Evaluation

Ethics and consent

Ethical approval for this study was granted by the Cross-School Research Ethics Committee at the University of Sussex (ER/DM465/1) and The Sussex Partnership Trust Quality Improvement Team registered and approved this quality improvement project. All participants involved in this study provided ~~fully~~ informed written consent and were informed that any data such as quotations retrieved and reported from interviews would be anonymous. All researchers followed British Psychological Society guidelines on conducting research.

Study design

A qualitative study design involving semi-structured interviews was utilised.

Participants and Recruitment

Semi-structured interviews were conducted with a total of eight participants (three patients and five clinicians) which is considered an acceptable sample size for a small qualitative study (Braun and Clarke, 2013). Although only three patients were recruited, the focus on patient needs during transition (which both groups had first-hand but differently situated perspectives on), meant that data triangulation could be achieved (Thurmond, 2001).

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~~(Thurmond, 2001)Thurmond, V. A. (2001). The Point of Triangulation. *Journal of Nursing Scholarship*, *33*(3), 253–258. https://doi.org/10.1111/j.1547-5069.2001.00253.x~~

All patients met the inclusion criteria of being discharged from an IP unit within three months of being interviewed and all participants were deemed to have capacity to participate by their responsible clinician. Although demographic information was collected on patients, patient characteristics are not described, due to concerns around identifying patients given the small sample size.

All clinicians who were recruited worked within SEDS. Four female and one male clinician were recruited to the study, comprising a clinical nurse specialist, two eating disorder practitioners, a health care assistant and a cognitive analytic~~al~~ therapist. Purposive sampling was used to recruit patients who were identified at a weekly IP bed allocation meeting which occurs within the clinical team. Fourteen patients were eligible to be interviewed during the timeframe of this study. A member of the research team contacted patients by telephone explaining the purpose of the ~~QI~~ case study. If interest was expressed, a Qualtrics link with relevant information sheets, consent forms and a demographic questionnaire was sent to participants via email with a unique participant identification pin. A spreadsheet of identification pins was stored on a password protected SPFT server. Patients were informed that they would receive a £10 voucher thanking them for their participation in this study.

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Five out of 25 clinicians working at SEDS were recruited via opportunity sampling. The project was advertised via an email which was circulated to the whole clinical team. Clinicians were informed to respond if they were interested in participating. Information and consent forms were then sent, and an interview time was scheduled.

Procedure

Interviews were conducted virtually via Zoom and lasted between 25 and 55 minutes (*M*= 34.2, *SD= 12.2*). Interviews were conducted by two members of the research team in a confidential setting.

By conducting semi-structured interviews, we were able to explore the research topic in a flexible manner and uncover new insights. Topic guides for the interviews were informed by phase one of the intervention co-development process. Interviews with patients centred on their experiences of IP admission and transition from IP to OP care as a way of understanding their needs during this period, ~~, their experience of transition from IP to OP care~~ and perspectives on the discharge pathway. Clinicians were interviewed about their experience treating patients discharged from IP care (for the same reason), perspectives on the discharge pathway and any barriers they anticipated when implementing a novel intervention.

All interviews were audio recorded and transcribed verbatim by the lead author of the study. Transcripts were anonymised and each participant's identification pin was allocated to their interview transcript to maintain their anonymity. Any other names mentioned, or names of IP units discussed during patient interviews were also removed. Sample size was determined by when sufficient information power was judged to have been obtained (Braun and Clarke, 2021), which was met with clinician participants. Due to low response rates, sufficient information power was not achieved for patients.

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Data analysis

The interview transcripts were analysed using framework analysis, a five-stage method for analysing qualitative data (Gale *et al*, 2013). This inductive approach was chosen as it allows priori research and new themes to be combined. Given the findings explored in the scoping search, it was crucial to consider these but also to allow new themes to emerge.

The team conducting analysis of the data consisted of the main researcher, an additional researcher working within the SPIRED research team, a SEDS assistant psychologist and a member of the ~~LEAP panel~~lived experience advisory panel who had lived experience of ~~IP~~ ED treatment. Using a varied coding team enhanced reflexivity in this study and reduced the risk of being misled by individual's prior interpretations.

All interview transcripts were read by all members of the coding team who then subsequently met to discuss initial themes which emerged during this familiarisation stage. An initial thematic framework was then identified based on these ideas. A process of indexing was then followed where all transcripts were double coded according to these themes and any discrepancies were resolved. The main researcher then generated an Excel spreadsheet with the indexing scheme and extracted quotes. Finally, the team met to discuss the charted data, which led to the selection of final themes and sub themes.

Results

Data obtained from patient and clinician interviews was classified into six thematic categories ('Service Provision', 'Relationships', 'Autonomy', 'The need for holistic patient care', 'Difficult Experiences', and 'Feedback on the pathway' and thirteen sub thematic categories.

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Theme 1: Service provision

This theme captured systemic factors which were viewed by both participant groups as ~~important~~being important to patients during ~~and after their~~ IP admission, and in the transition to OP treatment.

1.1: Accountability

Two patients discussed how being reminded of their recovery goals or having expectations set by their clinician which were regularly monitored was vital in continuing progress they had made during treatment:

> *One thing I've found really helpful is that she's emphasized the accountability…she's not going to not let me make progress now I'm out.*
>
> (Patient 1011, Female)

One patient recalled a previous discharge experience where she felt goals and activities were not followed up and explained how this affected her motivation and preparedness to tackle her ED:

> *Often, we had planned to do something, and it never came into fruition…*
>
> (Patient 1014, Female)

1.2: Consistency

All patients and two clinicians stressed the importance of regular contact following discharge to avoid gaps in treatment. Clinicians also explained that patients often benefit when there is communication with the OP service during an admission:

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I saw someone today… and she was like…I feel amazing. She said on the day she left, she had a phone call from her practitioner, and she was like, she's been really supportive. (Clinician 2004,)

Responses suggested that this was also important in building trust within the therapeutic relationship:

… it really helped me when I got out because I already had a relationship with her. It wasn't like a random person to weigh me but someone who I know and someone who I trust (Patient 2009, Female)

1.3: Service constraints

All clinicians acknowledged that systemic factors within the service may affect how patients experience discharge as well as how successfully the discharge pathway is implemented. Factors included a lack of clinician time due to capacity and a lack of resources:

I know that cannot be helped by any person, but I do feel like at the minute there is just a lack of everything. (Clinician 2004)

Theme 2: Relationships

This theme captured how the relationships patients have with other patients and staff can both be a supportive and interfering.

2.1: Feeling understood is important

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All patients and three clinicians expressed that feeling understood was paramount in getting through their admission. Participants suggested that this connection was often productive for patient recovery and for minimising feelings of isolation:

> *… they [patients] say like the staff can be great but it's the people around you who know what's going on and you're all in the same boat.* (Clinician 2004)

2.2: Triggering relationships

In contrast to Theme 5.1, all patients and three clinicians reflected on how relationships between patients can be fuelled by competition which can be triggering:

> *…but also, everyone is very competitive, and it does get hard sometimes with behaviours you have to witness.* (Patient 1011, Female)

Patients suggested that mealtimes could be particularly triggering. In terms of the discharge pathway, one patient suggested that since these interactions will be less frequent than on a SEDU, this reduces the chance of the group being experienced as triggering:

> *Um, yeah, it gets to a point where being in an environment surrounded by EDs can be more detrimental but if it's not 24/7 if it's just a once-a-week group, that's very different.* (Patient 1007, Female)

Theme 3: Autonomy

The majority of participants discussed the limited control patients had during their IP admission and were able to make few decisions about their own treatment.

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3.1: Loss of Adult Autonomy

All patients said that they found several aspects of their admission to be infantilising. One patient explained that their independence was removed when they were admitted and explained how most decisions during their admission were governed by staff:

> *… It's quite strange being an adult and not having the ability to make decisions for yourself, even in relation to, can I go outside right now?* (Patient 1007, Female)

> *Because a couple of people have sort of said… 'why is she treating me like a child I'm older than her?'* (Clinician 2002,)

3.2: Issues of control and power in relationships

All patients and two clinicians explained how relationships on the ward can be experienced as controlling due to the perceived power imbalance between staff and patients:

> *…but I felt it was very coercive, you know my Mum has actually said she thinks my mental health is worse now as well.* (Patient 1014, Female)

> *there's lots of meetings about them, for them, so again their sense of self or thinking about their own recovery tends to be taken away from them.* (Clinician 2005)

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Although some control over a patient's nutritional intake is often necessary, even life saving, in order to avoid the physical complications associated with EDs, the data suggests that the removal of a patient's ability to make decisions is often perceived during the admission as untherapeutic. Contrastingly, one patient believed that this control was imperative in her treatment and helped her progress in her recovery:

> *I found it quite helpful in the way that all the control is taken out of your hands.* (Patient 1011, Female)

Theme 4: The need for holistic patient care

This theme captured how patients felt they were not seen beyond their diagnosis due to the overemphasis put on weight restoration.

4.1: Emphasis on BMI

All patients believed that there was an intense focus on their weight during IP treatment whereas other important treatment goals were neglected:

> *I think for lots of people when you come out is when the mental work starts… you just have to get on with your meal plan.* (Patient 1011, Female)

> *… if you're not showing the physical progress, all fingers are being pointed at you…It didn't feel like treatment, it felt like a feeding farm.* (Patient 1014, Female)

This lack of alignment between treatment goals and patients' desires further contributed to the lack of autonomy patients described in Theme 1. There was also a strong indication that

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weight was treated in relation to a reward system whereby weight loss or gain dictated the freedoms patients had access to.

4.2: The need for an Occupational focus

According to all patients and two clinicians, occupational activities made patients feel recognised beyond their ED and helped them develop new hobbies:

> *…And it's not all about food, it's about, I'm a very creative person so they [the unit] pushed that... It made you feel like a person.* (Patient 1014, Female)

A lack of occupational activity, likely due to the emphasis placed on weight gain highlighted in Theme 2.1, often resulted in dissatisfaction towards an IP treatment. Although occupational approaches were seen as important, patients were dissatisfied with activities that felt like just distraction, consistent with Theme 1.1:

> *So, they tried their best to keep you occupied, but I knew at the end of the day that drawing a picture of a flower wasn't going to cure my eating disorder.* (Patient 1007, Female)

Theme 5: Difficult experiences

This theme captured the challenges that some patients face during IP care as well as obstacles they may encounter following discharge.

5.1: Distressing experiences during admission

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Although IP care aims to provide more intensive support compared to the community, all participants recognised how the IP environment can be difficult for some patients. This may be due to witnessing other patients in distress or the treatment that they received themselves:

> *So yeah, someone who is, actually still an inpatient [has seen] like self-harm and things …and feeling as though their responsible to stop someone head banging…* (Clinician 2002)

> *urm quite a threatening atmosphere…I just felt very frightened. I know my Mum thought I wouldn't make it out alive because I was so distressed all the time… they were playing a game of guess her BMI. It was just disgusting.* *(*Patient 1014, Female)

One patient reporting hearing inappropriate conversations from staff about patients which she found distressing. In contrast, one patient expressed overall positive sentiment towards her admission:

> *It's a big shock but it jumpstarts the recovery… I found that aspect helpful.* (Patient 1011, Female)

This suggests that experiences of admission differ amongst patients highlighting how both the positive and negative experiences need to be acknowledged following discharge, and the importance of trauma-informed approaches in discharge care.

5.2 Differences between the ward and the community

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All clinicians and two patients revealed that although the IP environment can sometimes be challenging, differences between the IP unit and the community can make the transition period from IP care difficult. Firstly, patients discussed how it felt more acceptable to talk about their ED during their admission compared to in the community:

> *It is quite strange going from an environment where everyone knows and understands into the real world where it's not as conventional to talk about your experiences… this led me to feel that even though I was desperate to go, that sense of attachment to that anorexia world.* (Patient 1007, Female)

Clinicians and patients recognised how the regimented structure of the IP ward is often incompatible with life in the community. Patients suggested that it can be difficult to be flexible around mealtimes after following a structured regime during their admission:

> *I think there's definitely challenges around trying to help them adjust to life again… so trying to work with their meal plan and how that actually fits into day-to-day life has been challenging.* (Clinician 2002)

Theme 6: Feedback on the pathway

This theme captures current perspectives and recommendations for adaptions to the pathway, based on staff and patient perspectives on the challenges faced during IP admission and transition to OP care..

6.1: Perspectives on the four components

Feedback was gathered for all four components of the proposed discharge pathway. Feedback on the supported eating group varied amongst patients and clinicians. All patients expressed anxieties around this group with two expressing that it could function as a reminder of supervised eating during their admission which some patients found coercive:

> *I don't think it would be something I'd want to engage in. I think for me the supported eating environment it acts as a reminder of my experience.* (Patient 1007, Female)

> *…that's one of the big motivations coming out of hospital is that you don't have to see that sort of thing [supported eating].* (Patient 1011, Female)

Clinicians comparatively believed that this group would act as a therapeutic space:

> *I think a place where we can really normalise it. I think eating with people is quite challenging for lots of patients so to have that safe environment where they can come.* (Clinician 2002)

The action for recovery group was favoured amongst all participants. One patient expressed how this group could reduce uncertainty by providing patients with a clear recovery plan that they have autonomy over:

> *But I thought that [action for recovery group] would be good to maybe recognise each patient's own triggers whilst helping them work it out for themselves…* (Clinician 2004)

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One patient and one clinician suggested that the ability to share this plan with people would help keep them accountable thus reducing their chance of relapse:

> *I think they are quite beneficial though, not always for myself but for someone else so they can pick up things really, before it reaches crises.* (Patient 1014, Female)

The psychology group was generally accepted amongst participants. Patients and clinicians expressed how having a space to process experiences which had been traumatic whilst on an inpatient unit ~~acknowledge and learn how to manage difficult emotions~~ would be advantageous. Clinicians also explained how this group could help patient foster compassion towards themselves:

> *Um. And I think getting over the individual distress caused by that could be beneficial.* (Patient 1007, Female)

> *If you look in terms of schema…, they're constantly unkind to themselves. So, learning to be compassionate… and learning to be resilient… I think is key.* (Clinician 2005)

Similar to the supported eating group, perspectives on the recovery through activity group varied based on how patients had experienced occupational activity during their admission. One patient cautioned that this group could acts as a reminder of coercive activity on the ward:

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> *I think again I wouldn't want to engage in this one in some ways for similar reasons to the supported mealtimes and it being a reminder of forced activity.* (Patient 1007, Female)

Positive feedback from participants included how this group could provide a way to manage difficult emotions and encourage healthy coping mechanisms.

> *… they may associate it in quite a soothing way but we kind of hope it could be a building block of learning how to tolerate doing an activity outside of their disorder.* (Clinician 2005)

6.2: Recommendations or amendments to the pathway

A significant recommendation which emerged from both patients and clinicians was the need to include a dietetic component within the pathway. Patients explained how they felt unaware of what their nutritional needs were especially after having these decisions taken from them during their admission. Patients also explained how there was a lack of information about physical exercise and how to incorporate this healthily:

> *there was little or no support about physical activity … people forget that exercise is a big or bigger struggle with lots of people.* (Patient 1011, Female)

To reduce the anxiety around groups, clinicians with experience of running psychological groups suggested that meeting with the facilitator beforehand could be useful in alleviating

patients concerns. This is conjunctive with theme 4.2 where patients valued consistent care which helped develop trusting relationships with staff:

> *… maybe making sure they meet with the facilitator beforehand… so then when they join it's not like they don't know anyone.* (Clinician 2002)

Discussion

~~This study formed phase two of the intervention development process shown in figure 1.~~ This paper was designed to understand patients' experiences of IP treatment in addition to their experiences of transitioning from IP to OP care. This is in accordance with MRC guidance ~~(Skivington *et al*, 2021)~~ which ~~highlights~~ recommends that complex intervention research should expand beyond determining whether an intervention is effective to ~~. The guidelines suggest that~~ understanding how interventions work, as well as how they interact with the environment (Skivington *et al*, 2021) ~~is crucial in maximising efficacy~~. It is therefore crucial to understand patients' experiences of IP treatment to enable targeted support after discharge from IP. ~~determine what support they will require after admission.~~ This study also aimed to provide preliminary evaluation of the acceptability of a discharge pathway for individuals transitioning from IP to OP ED care. While we used semi-structured interviews to allow for a range of responses, participants' narratives primarily focused on their IP experiences and less so on their experience of transition. The following themes emerged during such discussions: autonomy, the need for holistic patient care, and difficult experiences and relationships with other patients. The themes supported the ~~first~~ second ~~aim~~ objective of ~~this study~~the nested qualitative component and also contributed to the second ~~aim~~objective, by revealing why certain accepts of the pathway may be acceptable or not. One

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theme raised factors which were important for patients when transitioning to OP care, including consistency of care. The final theme captured positive feedback on the discharge pathway, as well as concerns particularly regarding the supporting eating group, which was felt to remind patients of difficult IP experiences. This supported the study's second aimobjective. The salient themes in this study will be discussed below in addition to the implications this has for modifying the discharge pathway before it is implemented and evaluated during phase three of the intervention co-development process. We sent a full write- up of this study to all participants to ensure they were satisfied with the way their experiences were documented.

Findings and Implications for the discharge pathway

Clinicians and patients expressed that IP treatment often left patients feeling infantilized and powerless in their relationships with staff. Despite the necessity of compulsory treatment for AN if patients' physical health is compromised (5), our analysis suggests that patients were dissatisfied with this loss of independence and believed this negatively impacted their mental health. In contrast, one patient recognised how this loss of autonomy was crucial in enabling her recovery. This conflict has been found in other studies which highlight the benefits of having limited control over decisions, while underlining how this can also be harmful to patients in terms of psychological outcomes (Offord *et al*, 2006). The broader psychological literature suggests autonomously motivated people have better treatment outcomes and that coercion can reduce engagement (Bindman *et al*, 2005). Consequently, it was felt important that all elements of the discharge pathway encourage patients' sense of autonomy. This is especially relevant when considering the supported eating group which participants expressed could act as a reminder of involuntary

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treatment during their admission. Other qualitative studies confirm this, with patients previously comparing mealtimes to battlegrounds (Long *et al*, 2012).

Another key theme which emerged was 'the need for holistic patient care'. Participants explained how they felt dissatisfied with the emphasis on weight gain during IP treatment. Given that AN is associated with adverse effects on cognitive functioning due to patients' low body weight, weight restoration is often crucial in enabling patients to engage in therapy. However, it was suggested that despite gaining weight, patients received minimal psychological support. Patients also explained how their freedoms, such as the ability to go outside, were dictated by weight rather than psychological progress. Research has shown that an emphasis on weight alone in AN treatment can lead to an increase in ED behaviours (Rance *et al*, 2017). In order to reduce patients' probability of relapse following admission, it seems imperative that discharge support includes factors which were neglected during IP treatment.

When evaluating the acceptability of the discharge pathway, patients emphasised the need for it to be holistic in nature. Participants suggested this could be achieved by including a dietetic and physical exercise component, something which is often unavailable during IP treatment. The use of nutritional psychoeducation has previously helped patients understand what a normal eating pattern is (Beukers *et al*, 2015), which is especially useful when returning to life in the community. Furthermore, patients reflected how incorporating a physical exercise component would be useful in helping them to understand how exercise can be incorporated healthily back into their lives. This confirms other qualitative accounts in which patients have suggested that a lack of normal activities on the unit can make adjusting back to OP care difficult (Offord *et al*, 2006).

Another important theme which emerged during this study was relationships with other patients, in addition to the importance of consistent relationships with staff. In terms of

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peer relationships, participants reflected upon how these relationships helped them to reduce feelings of isolation due to the mutual understanding of each other's difficulties. However, patients explained how these relationships were often triggering, especially if peers were at a different stage in their recovery. When discussing the discharge pathway, participants discussed concerns that component groups of the pathway could be triggering, providing support for the study's second ~~aim~~objective. Previous literature confirms how these relationships can either facilitate recovery (Offord *et al*, 2006) or be detrimental due to feelings of comparison and competition. Triggering relationships have also been found to strengthen ED beliefs (Colton and Pistrang, 2004), hindering recovery progress. Understanding these experiences is important when considering how the group dynamics of the discharge pathway will need to be managed. The above findings illuminate how there will be a need to set clear boundaries and 'rules' of what behaviours are not appropriate for the group setting. The group facilitator will also be fundamental in each component group in encouraging patients to remain independent in their recovery, regardless of what other group members are doing.

In terms of relationships with staff, patients evoked the importance of consistency in building trusting relationships with clinicians. Patients explained how remaining connected with their OP treatment team during their admission was beneficial because once they had been discharged, they continued seeing the same clinician. This consistency patients believed was important in sustaining progress made during IP treatment. This corroborates other findings which highlight that, when an OP treatment team is involved during the IP treatment process, patients are more likely to develop trusting relationships (Aftab *et el*, 2019). Understanding these previous experiences supports the first ~~aim~~ objective of the study, helping to inform how the discharge pathway is refined. Responses suggest that patients may

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find it beneficial to meet with the discharge pathway facilitators during their IP treatment, so these relationships can be established before discharge happens.

Strengths and Limitations

This study benefited by recruiting both patients and clinicians to better capture experiences of IP treatment. Recruited clinicians worked in various disciplines within SEDS, allowing for a broader range of perspectives to be considered. Adaptations to the discharge pathway have been facilitated by these qualitative responses and have contributed to the iterative process of developing this pathway to ensure it is suitable for its users. During a final focus group with clinicians from SEDS, the findings from this study were presented so that refinements could be made before phase three of this intervention development process, shown in Figure 1. During this focus group, patients' concerns surrounding the supported eating group were considered. Clinicians suggested that a recreational activity, alongside eating could be beneficial in ensuring that this group does not act as a reminder of supervised IP meals. This may increase the positive associations patients have around eating and enable them to transfer these skills outside of the group.

Although this study has provided important insights into patients' experiences and perspectives on the discharge pathway, the limitations of the study should not be overlooked. Firstly, all participants interviewed were recruited from one service (SEDS), limiting the generalisability of the findings, especially given the variations in ED treatment provision. Additionally, due to the low response rate when recruiting patients, the qualitative findings from this study reflect experiences from only a small number of patients. Given that there was variability in these responses, we would expect that a larger sample would have revealed other themes around IP experiences while also validating the responses in this study. This necessitates further investigation with a larger, diversified group of participants. Nonetheless,

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best practice guidelines for framework analysis were followed throughout and efforts were made to enhance reflexivity such as using the lived advisory panel during data analysis (Veseth *et al*, 2017).

Conclusions

Although this was a relatively small-scale qualitative study, interviews ensured that patient voices and experiences of IP treatment informed the development of the IP pathway. Although IP care is only encouraged when a patient's health is significantly compromised, an understanding of why some patients find this treatment difficult has clear implications for what discharge support will be needed. Crucially, the finding that patients' experienced feelings of powerlessness suggest how support should be collaborative and patients' autonomy to should be encouraged wherever possible. It is important that patient experience continues be considered in development of the IP pathway and evaluated through a follow-up study forming phase three of the intervention development process.

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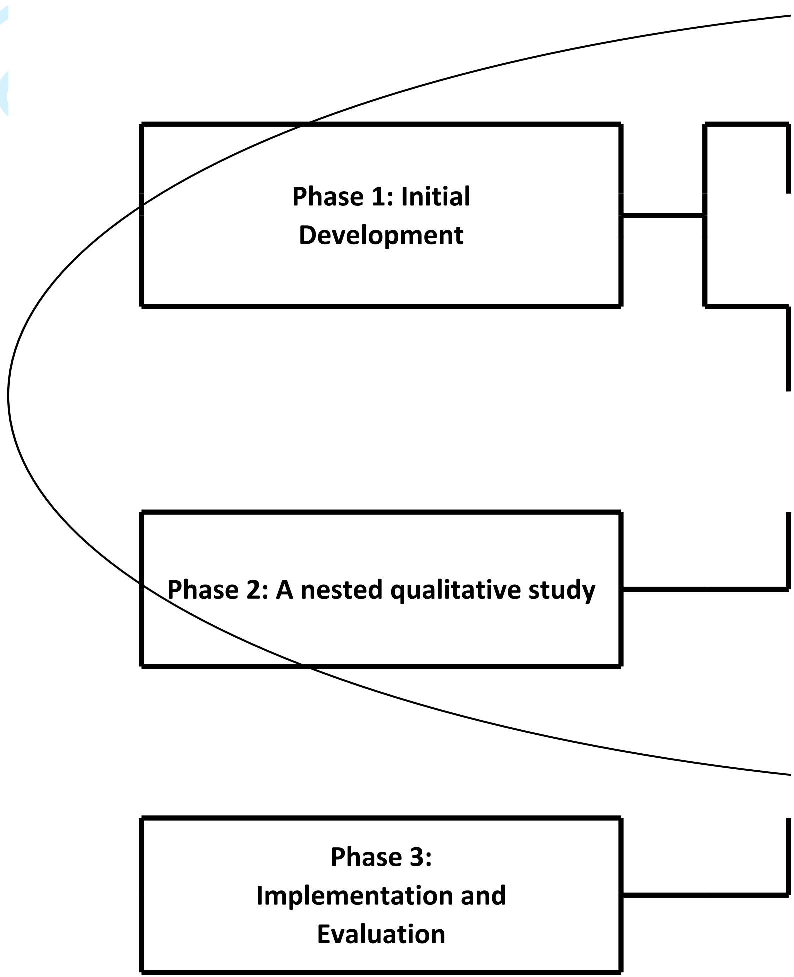

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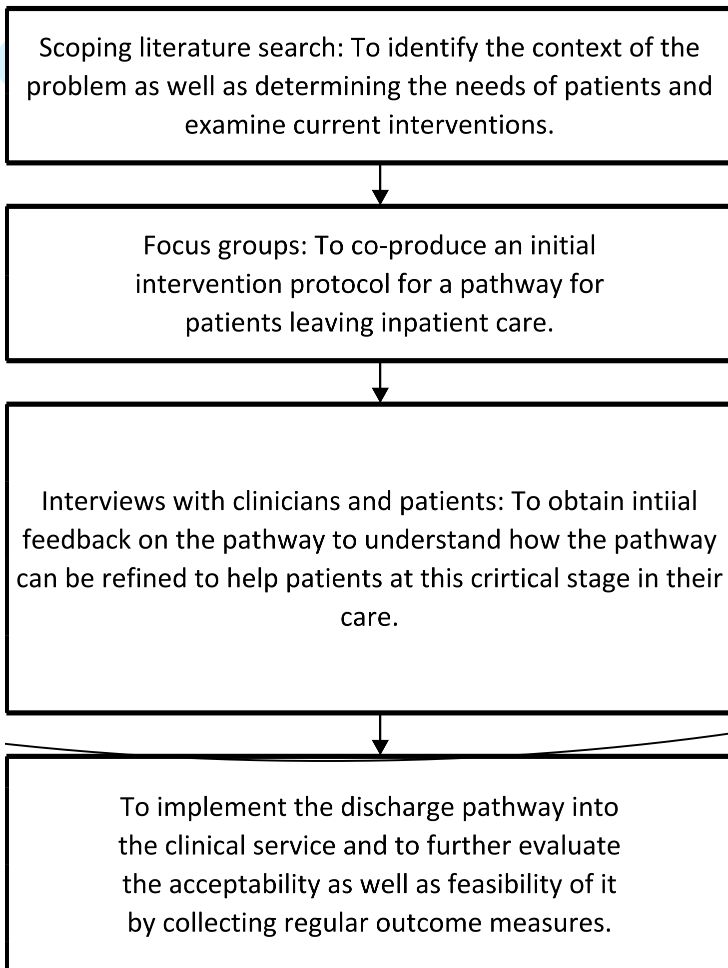

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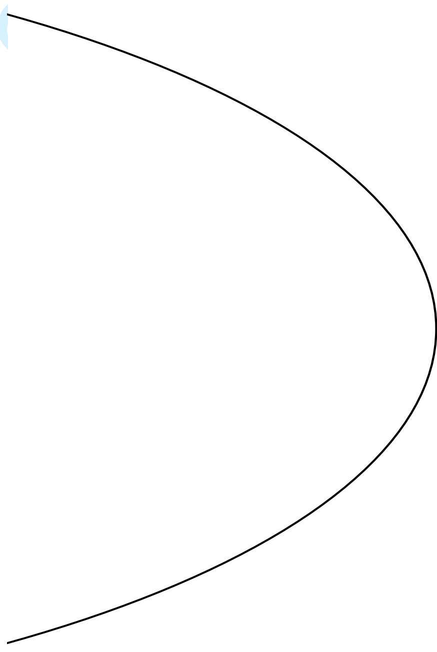

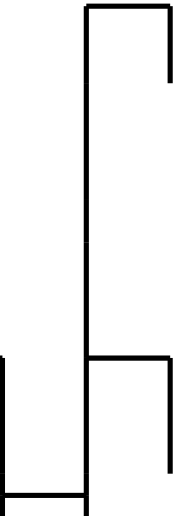

Discharged from hospital: After discharge from IP care, a patient is referred into the four different components of the discharge pathway by their lead

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practitioner. Patients are able to choose which groups to attend.

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Supported eating group: This will be an open supportive lunchtime group run by two members of the clinical team. This twice weekly group aims to support the transition around leaving hospital where patients have previously had support and supervision at every meal. Additionally, this groups aims to increase autonomy around eating whilst also reducing anxiety and shame around eating by providing helpful discussion and distraction during mealtimes.

Action in recovery group: This will be a weekly open group where patients will be encouraged to develop an ED specific recovery plan allowing patient to identify their own facilitators and barriers in their recovery.

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Psychology group: This will be a closed group aiming to create a safe space for patients to discuss the positive and negative aspects of their inpatient admission and provide support and practical strategies to help process and manage uncomfortable emotions. This group also aims to provide connection between group members in sharing their experiences to reduce isolation following inpatient admission.

Recovery through activity: This group will be a closed weekly group. The aim of Recovery Through activity is to increase awareness and understanding of the long-term benefits of occupational participation by exploring and experiencing a broad range of activities including music, art, IT and vocational activities.

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