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CASE STUDY

'Out There': Developing a transition pathway for adolescents and young adults with cancer using Experience-Based Co-Design

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SUMMARY
Experience-based co-design (EBCD) was used in the adolescent and young adult (AYA) oncology setting to develop a transition pathway from hospital for young adults completing cancer treatment. The EBCD methodology provides the opportunity to embed patient experience and input into service design. In this project staff and AYAs identified unmet needs and suggested working packages around psychological support, and provision of information about fertility, work, education, and relationships. Staff identified deficits in knowledge of survivorship issues for AYAs and interest in preparing AYAs for life after treatment.

Key Words
Experience-based co-design; adolescents; participatory action research; patient experience; cancer

ABSTRACT
This paper aims to briefly explain the use of experience-based co-design (EBCD) in the adolescent and young adult (AYA) oncology setting to develop a transition pathway from hospital to home for young adults following treatment. The EBCD methodology provides the opportunity to embed patient experience and input into service design and to co-design a service.[1]

BACKGROUND
Adolescents and young adults with cancer are a unique patient cohort with specific challenges and vulnerabilities differing from those of children or older adults.[2] A cancer diagnosis and treatment during this key transitional stage of normal adolescent development adds extra complexity to illness-related challenges.[2] The Improving Outcomes Guidance (IOG) for Children and Young People with Cancer suggests young people with cancer should benefit from expertise of tumour-specific and AYA-specific teams.[3] To support AYAs with cancer specialist services, specialist staff, and approaches to care delivery are required. Care should be age-appropriate, flexible, and individual to meet their specific needs.[2] Following cancer treatment, AYAs can feel disempowered, vulnerable, and have a loss of confidence. Interventions that facilitate empowerment can help improve health-related quality of life and coping.[4]

Quality improvement (QI) is the use of a systematic approach and methods to improve experience, outcomes, and care.[5] There is increasing interest in QI methods using co-production, where the experiences of service users are incorporated in the design of a service.[6] EBCD is a method of participatory service and QI that embeds the experience of service users and staff into service design.[1] The EBCD process involves collecting experiences of patients and staff through video interviews and workshops with staff and patients to identify touch-points (points of emotional significance), and prioritise areas for improvement.[7,8] The use of touch-points can help participants form a balanced view of positive and negative aspects of their experience, and thereby engage in service development in a meaningful way.[9] QI methods that positively engage and empower AYAs could support effective service design and individual patient empowerment through AYAs' engaging in the process.[6] In the context of pressures in funding and demand on

the National Health Service (NHS), efficient design and use of services are particularly pertinent.[10]

After completing cancer treatment, AYAs face unique challenges as they continue to transition into adulthood while adjusting to a change in the level of healthcare support.[11] Another issue is the difficulty engaging AYAs in research. Little EBCD research has been conducted in AYA oncology. One strategy suggested for addressing AYA engagement in research is using novel approaches such as framing co-design workshops with popular culture references, communication tools, and design methods.[12,13]

This project was set in a cancer centre in the United Kingdom. The centre has specialist facilities for AYA patients, including a multidisciplinary team of staff, and an inpatient and outpatient unit designed around the needs of this age group.[2] Patients remain under the care of their tumour specialist team while being able to access specialist psychosocial care and support, and peer support through treatment in an age-appropriate environment with other young people.

AIMS

The project had three principal aims:

1. To improve patient and staff experience through co-design of services at the end of hospital treatment for AYAs completing cancer treatment.
2. To develop a transition pathway from hospital to home and a recovery package suited to the needs of this user group.
3. To explore EBCD as a form of QI, involving young people in service design and improvement.

METHOD

The project plan was based on the EBCD toolkit and workshops from The Point of Care Foundation (PoCF). Key stakeholders were involved in developing the project plan. Stakeholders included: lead nurse, matron, lead clinician, nurse consultant, youth support coordinator, clinical nurse specialist, and service manager. Advice was sought from The PoCF team and internal governance approval was granted through the hospital service evaluation committee; additional ethical approval was not required.

EBCD has a six-stage process:[8]

1. Setting up the project.
2. Gathering staff experiences through observation and in-depth interviews.
3. Gathering patient and caregiver experiences through narrative-based video interviews.
4. Bringing staff, patients, and caregivers together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30-minute "trigger" video film of patient narratives.
5. Small groups of patients and staff work on the identified priorities (typically 4–6) over three or four months.
6. Celebration and review event.

The project included all six stages of the EBCD process (Figure 1). Stage 2 was adapted, the rationale and outcome of this will be explained in this paper. The AYAs and staff recruited in stage 1 are the same participants through all stages of the process. This paper will detail stages 1–4 of the project.

Stage 1: Recruitment

As a pilot project 12 participants were recruited overall, six staff and six AYAs. Staff were recruited through responding to an email invitation to take part, sent to members of the AYA team. Those selected included a range of specialities (Table 1).

Table 1: Staff participants

Staff member	Speciality
Medical Consultant	Oncology: Children and Young People
Matron	Oncology: Children and Young People
Clinical Nurse Specialist	Haemato-oncology
Clinical Nurse Specialist	Neuro-oncology
Clinical Nurse Specialist	Stem cell transplant/ Teenage and Young Adult Oncology
Senior Staff Nurse	Teenage and Young Adult Oncology

The lead nurse approached AYAs in hospital clinics or by telephone to invite them to participate. All AYAs

approached had received cancer treatment and care at the hospital and were six months to two years' post-completion of treatment. Those selected were a mix of male and female; had a range of ages; and had differing diagnoses, including solid tumour, neuro-oncology, and haemato-oncology.

Stage 2 & 3: Individual AYA and staff interviews

Stage 2 was adapted so that both staff and AYAs were interviewed and all interviews were video recorded. Video recording of interviews was done for both staff and AYA in order to give each group equal experience of engagement in the EBCD process. The interviews were semi-structured and all were conducted by the lead nurse, lasting on average an hour per interview. While it was recognised that using existing EBCD "trigger films" from a national archive can be effective in EBCD process,[8] there were no relevant films available to this aspect of AYA oncology, so new films were created. Audio recordings of the interviews were transcribed verbatim for analysis. A framework analysis was used to identify themes for interviews. Analysis was undertaken by three members of the team (CW, LS & TW). Selections of significant themes and touch-points were then shared and discussed to reach consensus. Nine themes were identified for each group (Table 2).

Table 2: Interview themes

AYA Themes	Staff Themes
Going home	Going home
Initial feelings	Initial Feelings
Preparing to go home	Information
Information	Work and study
Work and study	Relationships
Relationships	Independence
Independence	Support
Support	Hospital clinics
Hospital clinics	Resources and training

Sections of the patient and staff films illustrating the identified themes were then used to create two films for use in the subsequent patient and staff workshops. Each film was intended to be approximately 30 minutes long.[7] AYAs and staff were all offered the option of viewing their video independently prior to the workshops and were informed from the outset that they would have the option of removing any clips of their interviews from the final films at any point during the project.

Stage 4: Workshops

Three workshops were undertaken: one staff, one AYA, and one joint staff and AYA. Each workshop lasted approximately four hours and was facilitated by the project team. Participation in the workshops was voluntary and participants were not compensated for their time aside from travel expenses. Two AYAs and one care giver attended the AYA workshop event. Three staff attended the staff workshop event. Contact was made with all those who were interviewed before and after the event. Bowen et al.[12] found that teenage patients would engage with a co-design process best if it were structured around popular culture, flexible, and with creative interpretations of the method to suit this user group. It was decided that the workshops should include creative approaches where appropriate.

AYA workshop

The AYA film was 50 minutes long, longer than originally intended. The project team decided to review this version with patients in the first workshop, thereby enabling them to have input into how the film was edited and cut. When watching the film all the workshop participants were provided with pen and paper to provide selections of edits from the film.

An adapted emotional mapping exercise was facilitated, using each of the themes. The themes were written on large pieces of paper fixed to the wall. After watching the film, participants wrote words or phrases that resonated with them on post-it notes as touch-points. These touch-points were then placed under each theme section (Figure 2). It was then suggested participants reorder the touch-points by importance, however, they decided to group the touch-points instead. Participants then walked the project team around the mapped themes explaining the touch-points, how they had classified them, and which areas they had chosen to prioritise to work on.

Following the workshop, a summary was sent by email to all AYAs participating in the project, including those who could not attend the workshop. The film was then edited to 30 minutes, incorporating the suggestions from the group session.

Staff workshop

The process used with the AYAs was repeated in the staff workshop for consistency. Staff video interviews were

edited into a 36-minute film with clips arranged into nine themes. When watching the film, participants were provided with pen and paper to provide anonymous selections of what they thought could be edited from the film. From this process no additional edits were requested.

An adapted emotional mapping exercise was used. Using each of the themes, participants wrote words or phrases that resonated with them about on post-it notes as touch-points and attached the touch-points to each theme section (Figure 3). It was suggested participants reorder the touch-points into order of importance within each theme. Participants ordered some of the touch-points by importance, but also rearranged some touch-points into groups, combining two categories. Participants then walked the project team around the mapped themes explaining the touch-points they had identified, how they had arranged these, and which areas they had chosen to prioritise and work on. Following the workshop, a summary was sent to all the patients participating, including those who could not attend the workshop.

WORKSHOP OUTCOMES

AYA workshop

From this workshop, five "priority areas" were identified to work on:

1. Fertility advice
2. Counselling
3. Peer support–Facebook, Skype, events
4. Returning to work/study
5. Relationship advice

Suggested improvements included:

1. Mobile phones for clinical nurse specialists to use to communicate with AYA patients
2. Support groups for friends/family supporting AYA
3. Facebook discussions within the closed Facebook group run through the hospital around key topics such as fertility and relationships

Staff workshop

From this workshop, four "priority areas" were identified to work on:

1. Going home and initial feelings
2. Information
3. Fertility advice
4. Privacy and time alone

Suggested improvements included:

1. End-of-treatment summaries
2. End-of-treatment days/events
3. Written information/leaflet about the end of treatment
4. Information to be available online
5. Stratifying patients to appropriate community support
6. Mobile phones for clinical nurse specialists for use with AYA patients
7. Care plan, including psychosocial issues, to be completed for all AYA at the end of treatment and shared with them via email
8. Facilitate time alone in clinic for all AYA and communicate with them the rationale for this
9. Support with fertility and relationship advice at key points during and after treatment.

Future Directions

Stages 5 and 6 of the EBCD process are planned for this project with new QI initiatives to be embedded in the service following the outcomes.

DISCUSSION

AYAs often have low levels of engagement with survivorship care and research. This EBCD project has demonstrated good engagement with AYAs involved—contact has been maintained with all AYA participants throughout the project. Thirty percent (n=6) of AYAs attended the initial workshop session. Those who could not attend contacted the team with reasons, including illness and work commitments. Individual written feedback collected from the AYA session was rated excellent overall and included the positive experience of sharing experiences, feeling valued, and prioritising issues. Though being video recorded for interviews was a new experience for AYAs in this context, they reported the film made from their video interviews was useful in understanding other AYAs' experiences as they were able to see their body language when they were speaking. Similarly, staff reported a positive experience of sharing experiences and having the opportunity to reflect on a particular point in a patient's journey.

Staff members and AYAs were included from a range of tumour types and demographics, however, as AYA cancer services include multiple cancer groups, limitations of this study include the sample not being representative of all AYAs and staff. As has been previously noted in other EBCD cancer studies, though the AYAs involved in this project had different cancer types, they still reported a shared experience and priorities, regardless of their cancer type.[7]

EBCD is effective in actively engaging staff and users in a QI process. However, parts of the process, including training for the methodology, video interviews, selections and editing involve time commitments and specialist skills, are not necessarily readily available to frontline healthcare staff. QI strategies within healthcare organisations should support staff in the selection of projects appropriate for this methodology and in carrying out the process where appropriate.

CONCLUSION

Engaging staff and AYAs in QI is essential in the current healthcare landscape. EBCD provides a novel and unique framework for engaging AYAs in QI; embedding staff and AYAs' experiences into healthcare or service design. Further work is needed to support a wider range of projects and staff engagement with this methodology, particularly with AYAs.

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CONFLICTS OF INTEREST
No competing interests.

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ETHICS COMMITTEE APPROVAL
None

Figure 1: EBCD project process map

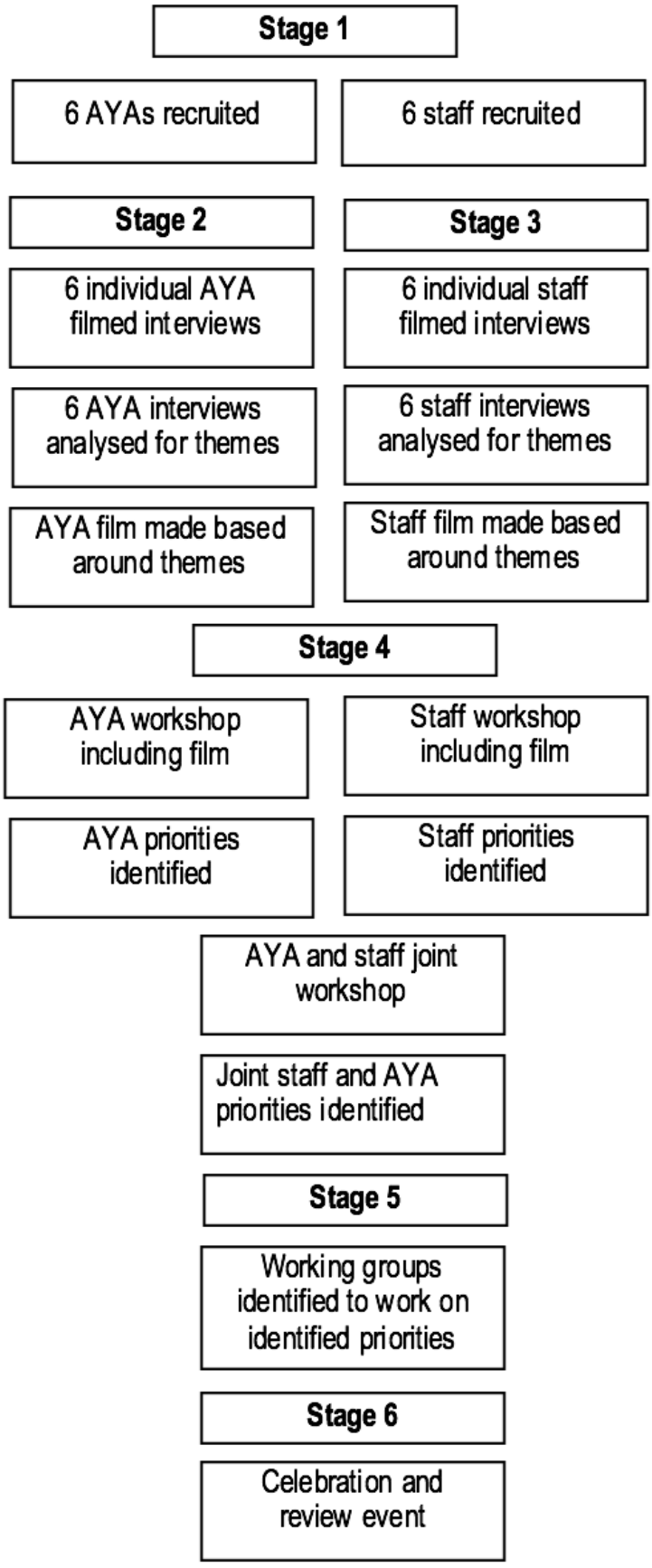

Figure 2: AYA workshop

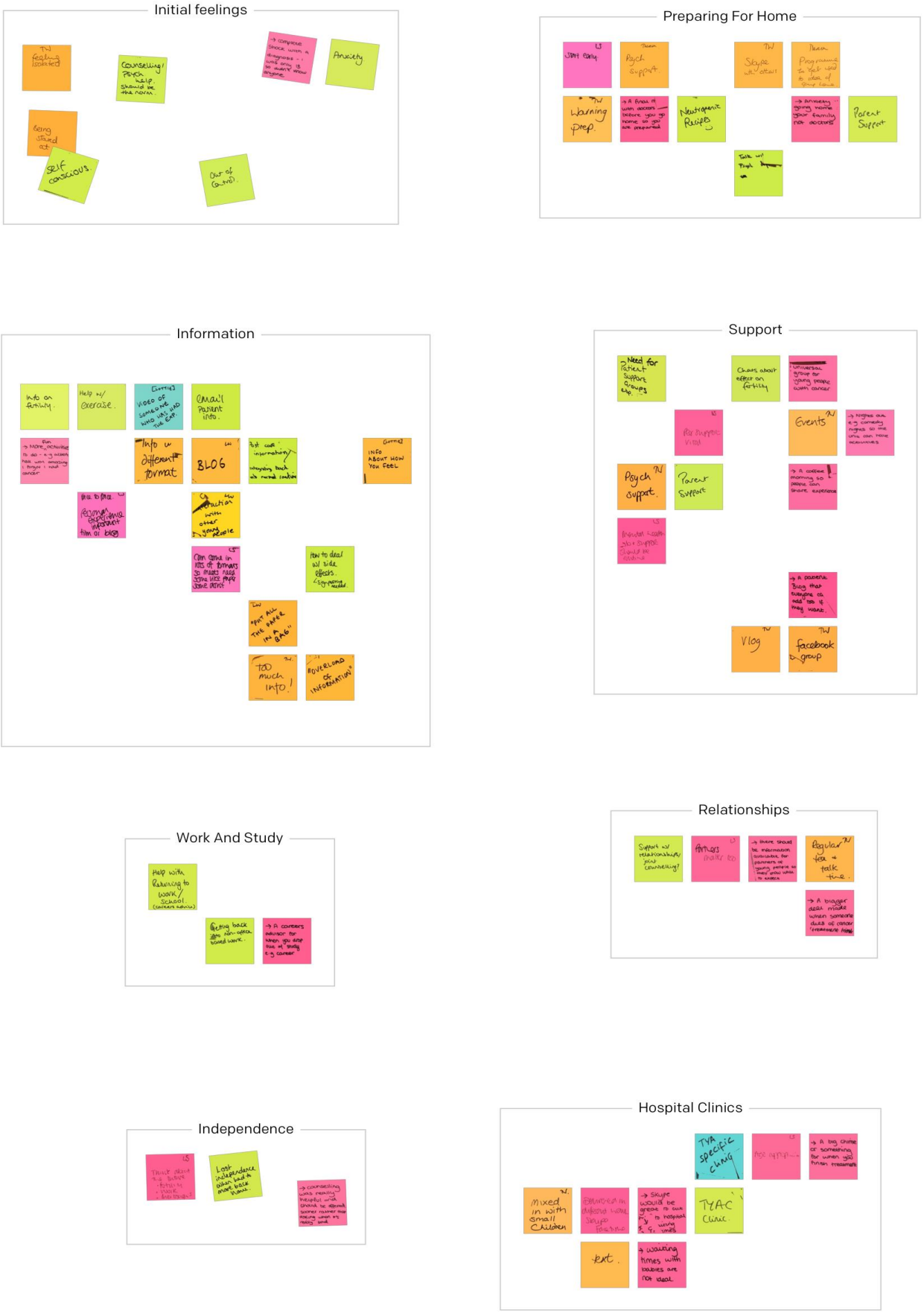
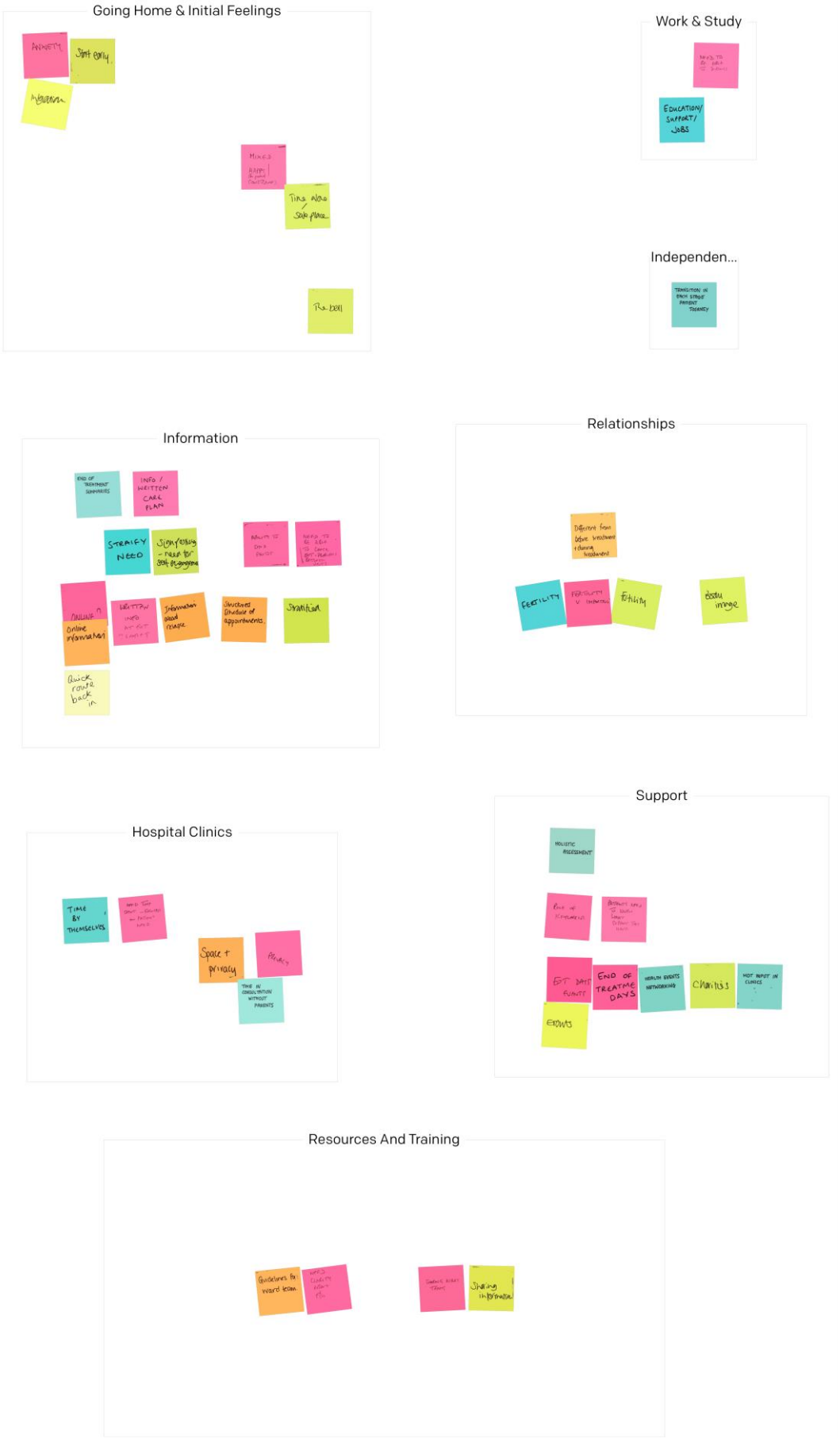
Figure 3: Staff workshop