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Improving personalised care and support planning for people living with treatable-but-not-curable cancer

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ABSTRACT

People living with treatable-but-not-curable (TbnC) cancer encounter cancer-related needs. While the NHS long-term plan commits to offering a Holistic Needs Assessment (HNA) and care plan to all people diagnosed with cancer, the content, delivery and timing of this intervention differs across practice. Understanding how people make sense of their cancer experience can support personalised care. A conceptual framework based on personal narratives of living with and beyond cancer (across different cancer types and all stages of the disease trajectory), identified three interlinked themes: Adversity, Restoration and Compatibility, resulting in the ARC framework.

Our aim was to use the ARC framework to underpin the HNA to improve the experience of personalised care and support planning for people living with TbnC cancer. We used clinical work experience to operationalise the ARC framework and develop the intervention, called the ARC HNA, and service-level structure, called the ARC clinic.

We sought expert input on the proposed content and structure from patients and clinicians through involvement and engagement activities. Delivered alongside standard care, the ARC HNA was piloted with patients on the TbnC cancer (myeloma and metastatic breast, prostate or lung) pathway, who were 6–24 months into their treatment. Iterations were made to the content, delivery and timing of the intervention based on user feedback.

Fifty-one patients received the intervention. An average of 12 new concerns were identified per patient, and 96% of patients achieved at least one of their goals. Patients valued the space for reflection and follow-up, and clinicians valued the collaborative approach to meeting patients' supportive care needs. Compared with routine initial HNA and care plan completion rates of 13%, ARC clinic achieved 90% with all care plans shared with general practitioners. The ARC clinic adopts a novel and proactive approach to delivering HNAs and care plans in a meaningful and personalised way.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Living with treatable-but-not-Curable (TbnC) cancer can be complex, involving various diagnostic and treatment pathways, and long-term follow-up across healthcare settings.
- ⇒ Personalised care is required to ensure people can take an active role in coproducing health and are supported to access appropriate supportive cancer care.

WHAT THIS STUDY ADDS

- ⇒ The Adversity-Restoration-Compatibility (ARC) framework can be used to underpin the design of patient-centred supportive cancer care services for those who are living with TbnC cancer.
- ⇒ The ARC Holistic Needs Assessment (HNA) enables patients to achieve self-management goals, to improve their well-being and improves the experience of personalised care.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The ARC clinic can be used as a baseline template for the likely outcomes of scaling to other cancer pathways and time points.
- ⇒ The ARC framework can be used to inform the coproduction of personalised care and to improve the experience of care for people living with and beyond cancer.

PROBLEM

Living with treatable-but-not-curable (TbnC) cancer can be a complex situation that often involves various diagnostic and treatment pathways, and long-term follow-up across multiple healthcare settings.[1] People who are living with TbnC cancer report that they experience uncertainty around the progression of their disease, describe difficulty in planning for the future, and require personalised care to meet their individual needs.[2 3] Holistic assessments (such as the Holistic Needs Assessment (HNA) in the UK (macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holisticneeds-assessment)), provide an opportunity to offer personalised care by empowering patients to work in partnership with clinicians to coproduce individualised care plans built on person-centred goals. However, the content, delivery and timing of this intervention differs across practice.[4 5]

To further support personalised care, it is important to understand how people make sense of their cancer experience. We conducted a systematic review and narrative synthesis and identified three inter-linked themes that describe the patient experience of living with and beyond cancer (LWBC); Adversity (realising the impact of cancer and treatment), Restoration (managing, coping and readjusting to new challenges) and Compatibility (reconciling and reflecting on how cancer has affected life), resulting in the ARC framework (visual representation of themes included in online data supplement (ODS) 1.[6] We then conducted a study to explore the shared experience of living with and beyond breast, prostate or colorectal cancer and identified three superordinate themes: (1) the cancer shock, (2) managing cancer and getting through and (3) getting over cancer.[7] These themes can be accommodated by the ARC framework, reinforcing the usefulness of a framework for services.

Aims and objectives

Funded by a 12-month RM Partners Personalised Care Project Grant, the 'ARC clinic' was developed and piloted by Imperial College Healthcare NHS Trust (ICHT) and ran from August 2019 to March 2020.[8] The overarching aim of the project was to improve the experience of personalised care and support planning for people on a TbnC pathway by developing and piloting an intervention that builds on the HNA and translates the ARC framework to practice. We wanted to find out if patients can be offered a new way of understanding their adjustment that promotes self-management. The objectives were to: (1) explore how to coproduce personalised care and support for those who are living with TbnC cancer, (2) support the identification of individual concerns and person-centred goals, (3) support people (at least 50%) to action at least one self-management goal, (4) identify possibilities for rehabilitation and improve the number of ongoing referrals (at least 30% of patients) for rehabilitation and supportive care, (5) improve communication with primary care by sharing at least 50% more care plans with general practitioners (GPs) compared with initial HNA care plans.

Background

Cancer is an increasingly common experience and a leading global cause of disease burden.[9] A predicted 5.3 million people will be diagnosed with cancer in the UK by 2040,[10] and approximately 29% of those will live with TbnC cancer.[11] This group of people live with cancer that, while treatment might slow the progression of disease, is unlikely to be cured.[2] The effects of cancer and cancer treatment for people living with TbnC cancer can be extremely disruptive and the process of managing illness can be non-linear and exhausting.[6 11 12]

There is increasing awareness that people who are living with cancer as a long-term condition, and who are supported to participate in their own health and care, have improved patient experience.[13] Additionally, when health services are designed to support personalised care, people have an improved quality of life and reduce their use of healthcare services.[14] The need to provide integrated personalised care and support for those living with TbnC cancer mirrors requirements for other long-term conditions such as heart disease, diabetes, stroke and mental health.[15 16]

The National Health Service (NHS) long-term plan offers a comprehensive model of personalised care and commits to offering a holistic assessment of needs and care plan to all people diagnosed with cancer as a core component of standard cancer treatment.[17] This process also recognises the importance and influence of the quality and nature of relationships between clinicians and patients. For example, a systematic review of the impact of the HNA found that the way in which the HNA was implemented (ie, the interaction) was more important to understanding patient outcomes than what was implemented.[18] Additionally, clinicians have indicated that the focus of HNA implementation is on meeting service targets (ie, the number of patients offered an HNA) rather than on promoting personalised care and support. While the HNA is designed as a starting point for supportive conversations, Briggs *et al*,[19] found that women with breast cancer were unable to raise psychological concerns and perceived it as more as a research tool for health services rather than for personal use.[19]

The need for a practice framework that draws on different illness models to deliver personalised patient-centred assessments of need and care has been highlighted.[4] The ARC framework makes a direct contribution here, by providing a conceptual framework developed from personal experience narratives.[6] Within the ARC framework, a holistic approach that addresses physical, emotional, social, functional and financial support needs, and that promotes quality of life is also required.[17 20] This requirement is echoed by a recent qualitative synthesis on the experience of cancer treatment that identified the need for a personalised holistic approach to improve long-term well-being and quality of life.[13]

Measurement

In line with NHS England Key Performance Indicator guidance, an initial HNA and care plan is offered within 31 days of diagnosis.[17] To measure change, we used individual outcome measurements from each patient's initial HNA including the number of identified concerns, the number of goals set and previous service utilisation as a baseline. These scores were then compared with HNA scores from the ARC clinic. In addition, data on the number of goals achieved and number of onward referrals to rehabilitation and support services were collected. Qualitative feedback from patients and other team members on the process and impact of attending the ARC clinic on health and experience of care and support planning was also collected (eg, was the intervention relevant/personalised?). In addition, in terms of service-level improvement, we measured the impact on key performance indicators, that is, ARC HNA and care plan completion rate and the number of care plans shared with primary care compared with initial HNAs.

Design

The aim of the ARC clinic was to shift patients' expectations from a more traditional transactional-medical encounter to being person-centred, offering a focus on strengths-based practice and self-management, rather than just 'providing.' Drawing on the concepts of psychological adaptation and coproduction, the ARC clinic offered a developmental process with reflection and storytelling, where the ARC framework was used to shape the narrative, to talk about the person's cancer experience, and to offer connections with other experiences.[21 22] The Template for Intervention Description and Replication checklist and guide has been used to report and promote the replicability of the ARC HNA intervention.[23]

Patient and public involvement and engagement

A steering group with clinical advisors from primary and secondary care and the voluntary sector was established to support project setup.[24] In addition, we involved and engaged clinicians and NHS senior leaders at the outset to provide insights in addressing context-specific improvement challenges and to identify any quality problems that occur at the interfaces between teams and/or organisations.[25] Consultations with senior leaders, clinical nurse specialists (CNSs), allied health professionals (AHPs) and GPs allowed for discussions on positioning, timing, operationalisation and configuration of the ARC clinic in the cancer pathway. The lead CNS and CNS teams responsible for personalised care in the TbnC cancer pathway were also consulted to ensure that the ARC clinic complemented existing practice. Additional feedback on content and projected outputs (eg, the coordination of rehabilitation services) was provided by the CNS teams and views regarding any concerns and/or support for the project were shared.

Patients were also consulted on the ARC clinic plans with a focus on operationalisation.[26] We gathered feedback on the suitability of the ARC terms and the language was translated from ARC to Action, Recovery and Change for use in practice. In addition, patients were invited to comment on clinic materials and information sheets and participate in designing a (1) clinic logo and (2) visual conversation aid that illustrates how the ARC themes can be used to support personalised conversations in ARC clinic consultation.[27]

1. The logo (included in ODS 1) illustrates a series of blue 'waves': the ARC themes are represented by upsurges and curves reflecting the fluidity of the adjustment process and demonstrating the changing nature of life following a cancer diagnosis.
2. The visual conversation aid (included in ODS 1) supports patients to work in partnership to complete an HNA and collaborative care plan that addresses what matters to them. The wave design is again used to represent each of the ARC themes—and as a guide to relate adjustment and personal experience, (eg, for some people, a wave might represent a ripple and for others, a shock wave). People are reminded that they can move back and forth as well as straddle across themes/waves at the same time.

Procedure

The ARC clinic was developed as a novel, reflective, adaptation-focused conversation, including HNA and self-management tools, to be delivered over three AHP-led interactions:

Interaction 1: Telephone contact with each patient to offer the ARC clinic invitation.

Interaction 2: Face-to-face outpatient appointment.

Interaction 3: A follow-up telephone consultation offered after 4 weeks to review each patient's goals and to gather feedback on the ARC clinic.

The ARC intervention had two components:

Component 1: interaction—partnership working

The relationship between clinicians and people who are living with TbnC cancer is central to personalised care. The intervention addressed the patient-clinician partnership by working in collaboration and by prioritising motivational interviewing techniques and solution-focused practice.

Component 2: structure—promoting personalised care and support planning

Personalised care and support planning was promoted through three specific working practices:

1. Offering a face-to-face HNA to identify concerns in different areas of life (practical, family, emotional, spiritual, physical or other concerns). This allowed for a focus on what matters to the person living with TbnC cancer and enabled them to have an active role in decisions about their care.
2. Using the ARC framework themes to structure conversations, to support patients to reflect on their cancer experience (eg, psychosocial adjustment and transitioning), and to offer connections with other experiences to provide a new way of understanding adjustment and that promotes self-management. A detailed example of the conversation script is included in ODS1. Figure 1 outlines the brief ARC clinic HNA conversation guide.
3. Codeveloping a personalised care plan to manage the identified concerns, to identify and build on strengths, to support goal setting and goal-striving, and for signposting to other local support services.

Intervention provider

The ARC clinic was set up as a therapies-led intervention after considering capacity and remit and following discussion with the CNS team. The focus was on rehabilitation and support, and the clinic aimed to complement standard care offered by CNSs on managing treatment and impact of treatment. The decision was made for a senior clinician to lead the ARC clinic due to the unfamiliar nature of setting up a new intervention for people

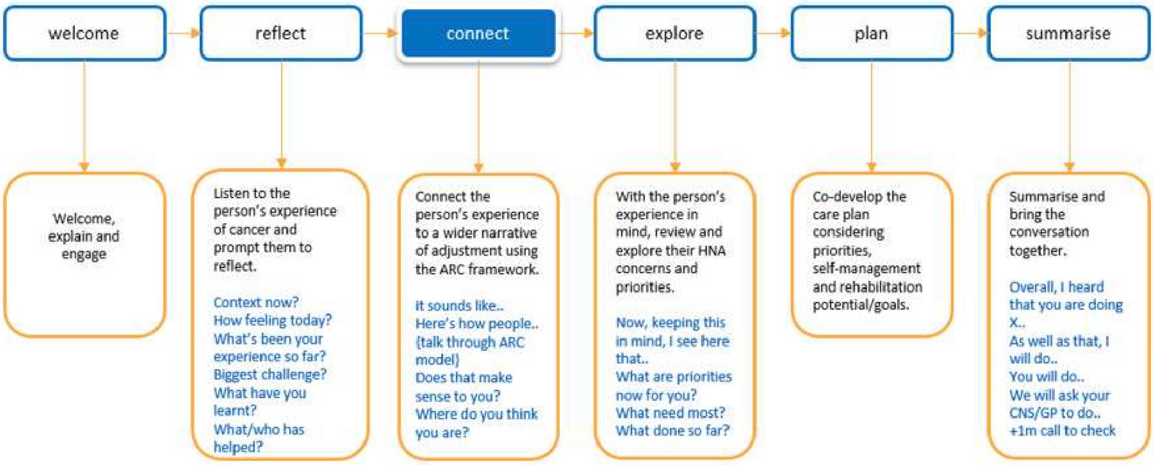

Figure 1 ARC clinic HNA brief conversation guide. ARC, Adversity-Restoration-Compatibility; HNA, Holistic Needs Assessment.

living with TbnC cancer at a new point in the cancer pathway. Conversations around uncertainty of the needs and concerns that might be raised by patients, having knowledge of how to provide support to meet those needs and concerns, skills in negotiating personalised goals and knowledge of available rehabilitation/follow-on services, an ability to provide tailored (and not general) advice, skills to work collaboratively and in partnership, and an ability to engage patients in reflection necessitated senior expertise. In addition, skilled communication was required to establish a new relationship, to invite patients who are living with TbnC cancer, and to gather feedback by phone. The ARC HNA was therefore delivered by a Band 8a (Agenda for Change) Occupational Therapist (1.0 Full Time Equivalent (FTE)), with follow-up support (1-month telephone call) from a Band 5 Assistant Psychologist (0.5 FTE). The occupational therapy (OT) service lead and consultant clinical psychologist provided strategic oversight and clinical supervision. In addition, OT aims to build on strengths and to identify personal meaningful goals that assist those living with TbnC cancer to shift from focusing on coping with a life-limiting illness to rediscovering important life roles that contribute to improved quality of life and well-being.[28 29] With this clinical background founded on participation and collaboration, OT was, therefore, considered well placed to be at the core of the intervention.[30 31]

Timing

We used process mapping to (1) determine the potential value of the intervention at different points of the healthcare journey, (2) identify which components of the intervention added value to the process and (3) assess where there may be waste or delays.[32] Effective personalisation of cancer support, in the context of advanced disease and ongoing treatment, requires focused attention to the psychological processes of adjustment and self-efficacy, and so the ARC HNA was offered at a critical, yet underused time point in the patients' cancer pathway, that is, 6–24 months postdiagnosis, which is typically after (or well into) the first treatment.[6] In this way, the ARC HNA was offered during active treatment to supplement the existing initial and end of treatment (EOT) HNA requirements. For some patients, the ARC HNA might be considered a replacement HNA, because there is often no EOT intervention for those who are living with TbnC cancer.

The ARC HNA was offered within an ARC clinic service-level structure, in addition to standard treatment (medical clinics and CNS support continued as usual) and was fully aligned with existing supportive cancer care services and other personalised care and support planning interventions (eg, https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/personalised-care). Figure 2 provides an illustration of the ARC clinic timing on the personalised care pathway.

Patient eligibility

Patients were eligible to be invited to the ARC clinic if they were receiving care from adult ICHT services on a TbnC cancer (metastatic breast, lung, colorectal and myeloma) pathway and were 6–24 months postdiagnosis. Patients who had identified high levels of distress (a high distress score) at their initial HNA (completed with a CNS and offered within 31 days of diagnosis as a part of standard care) were prioritised for the clinic. Potential patients were identified via local online health records or the Somerset Cancer Register and by direct referrals from CNSs. Due to the nature of advancing disease, individual patient case files were reviewed prior to offering the intervention and those who were receiving palliative care were excluded.

Strategy and improvement approach

The ARC clinic was set up as a clinical microsystem to provide care from a project-specific team to a particular group of patients. Clinical microsystems are a frontline approach used in healthcare systems to target

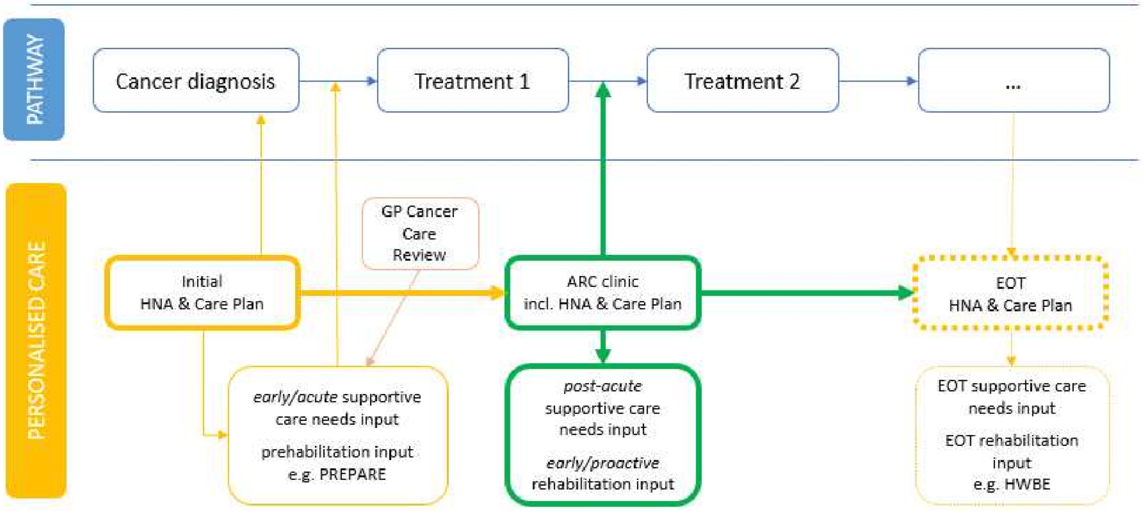

Figure 2 ARC on the personalised care pathway. ARC, Adversity-Restoration-Compatibility; EOT, end of treatment; GP, general practitioner; HNA, Holistic Needs Assessment; HWBE, Health and WellBeing Event

improvement efforts and to understand the quality of care delivery.[33] The clinical microsystem strategy is founded on the principle that the quality, safety and person-centredness of a whole healthcare system is determined by the performance of its constituent microsystems.[34 35] In this way, the ARC clinic was developed with a defined purpose and provided a specific unit of care within the wider cancer service at ICHT.

Table 1 Summary of ARC microsystem characteristics

Characteristic and operational definition	ARC clinic application
Integration of information Information is key, technology may be very helpful	The intervention was developed with oversight from a project steering group and patient and public engagement activities. We shared information about ARC with patients, clinicians, and senior leaders across primary and secondary care.
Measurement Microsystem routinely measures process and outcome data, feeds data back to providers, makes changes based on data	We measured patient-level outcomes using HNA and goal-attainment scores and collected qualitative feedback on the process and impact of attending the ARC clinic. We measured service-level outcomes in terms of uptake of rehabilitation referrals and HNA and care plan completion rates. We made iterative changes in response to the data.
Interdependence of the care team Care provided by a multidisciplinary team, information is key to the relationship	The ARC clinic was developed as a Therapies-led intervention to be delivered alongside standard care. Communication between secondary and primary care (in terms of sharing HNA and care plans with GPs) was also promoted.
Supportiveness of the larger system Microsystem views larger organisation as helpful	The organisation helped to shape the intervention. Senior NHS leaders and clinicians were consulted on the timing of the intervention and feedback was gathered on whether the proposed intervention would meet the identified quality improvement need.
Constancy of Purpose Integration of the aim throughout the microsystem	The intervention was developed to complement and as a solution to support standard of care practice and to free up CNS clinical time for other duties as well as to enhance the quality of care.
Connection to community Microsystem is a resource to the community, community is a resource to the microsystem	The project promoted patient engagement activities and worked closely with third sector services such as Maggie's to connect to the wider community.
Investment in Improvement Resources made available for improvement (training, money, time)	Funding was awarded to pilot the clinic for twelve months.
Alignment of role and training Health professionals expected to work at the upper limits of education, training	A secondment opportunity was available to a senior AHP and training available as required.

AHP, allied health professional; ARC, Adversity-Restoration-Compatibility; GP, general practitioner; HNA, Holistic Needs Assessment.

Table 1 maps microsystem characteristics to the ARC clinic.

Theory of change

The ARC HNA is underpinned by a conceptual framework for LWBC built on personal experience and adjustment theory. We proposed that the intervention could be used to improve personalised care and support planning for people living with TbnC cancer, by offering psychoeducation (ie, knowledge of the ARC framework and connecting to other peoples' experiences), goal setting and goal-striving opportunities, and by focusing on strengths and solutions. Alongside, we proposed that the intervention would shift patients' expectations from more traditional transactional-medical encounters and improve overall experience of care. Patients would be supported to coproduce health, leading to increased empowerment, well-being and quality of life. Clinicians would experience improved quality of practice through interdisciplinary working, and wider service-use would be improved with joint working across secondary and primary care.

RESULTS

Attendance

A total of 113 patients met the eligibility criteria and were invited to attend the ARC clinic. In total, 51 patients attended. Of those patients, 23 (45.1%) were male and 28 (54.9%) were female. In terms of cancer type, 18 (35.3%) patients had myeloma, 16 (31.4%) had breast cancer, 9 (17.6%) had lung cancer and 8 had prostate cancer (15.7%). The average age of patients was 62.9 years. Eleven patients (21.6%) attended the clinic with a carer.

Sixty-two people (55%) declined to take part. Reasons for declining were: 27 patients (across all cancer types) reported they had no needs (43.6%), 25 patients (across all cancer types) felt the ARC clinic would not meet their needs (40.3%), 5 patients (breast and myeloma only) reported they already had too many hospital appointments (8%), 3 (breast and myeloma only) were supported by other services (4.8%) and 2 (myeloma only) reported being unwell (3.2%). We identified that more patients declined the invitation in the breast (71%), prostate (69%) and myeloma groups (60%) and tended to report they were 'doing well', and therefore, did not need this input (44.8%). More uptake was noted in the lung group (61.1%). In terms of resource use, each patient received the three ARC clinic interactions (as outlined in the procedure). All interactions were personalised according to need, with face-to-face outpatient appointment times ranging from 30 to 60 min and follow-up telephone consultations ranging from 10 to 15 min.

HNA concerns

The clinic enabled an average of 12 more concerns to be identified per patient compared with their initial HNA. While more concerns were identified, the pattern of needs was similar to initial HNAs with the highest number of concerns falling in the physical domain (fatigue (n=29), pain (n=19) and getting around (n=17)) followed by emotional needs (thinking about the future (n=21), difficulty making plans (n=19) and sadness and uncertainty (n=16)). Nineteen people reported a practical need around exercise and activity and 18 people had a family concern regarding children.

Goal setting and care planning

Sixty-three new goals were set across the patient cohort at the initial ARC clinic visit. Goals related to walking (28%), sedentary leisure (24%), exercising (16%) and instrumental activities of daily living (14%). In total, 62% (n=39) of all goals were attained after 6 weeks. Where goals were not attained (n=24), there were 10 instances of goal disengagement and 14 instances of goal reengagement, that is, the generation of an adapted and more feasible goal.[36 37] In total, 96% of all patients were guided to achieve at least one of their goals. In terms of number of onward referrals to rehabilitation and support services, 37% of patients were referred to start new rehabilitation interventions and 53% were referred to supportive care services by the ARC clinic. Online data supplement 2 presents the findings (number of patient goals set and achieved) in visual form and illustrates the distinctive feature of the ARC clinic intervention that provides follow-up and measures goal attainment.

One patient reported an improved sense of self-management and valued the holistic nature of the intervention and the opportunity to be referred on to other support services:

> It gave me a structure and framework to audit ideas for making personal goals, I felt like I was seen as a whole person. Without coming to the ARC [clinic] I wouldn't have gone to Maggie's. It's stimulated me to think about what I could do to help myself.

Another patient spoke about the benefit of support in terms of managing their fatigue and the usefulness of the ARC HNA in terms of beginning to understand and validate their own experience of living with TbnC cancer:

> Pacing, planning, prioritising was useful, and fatigue DVD was wonderful. Managing to keep active at home, implemented fatigue strategies into life and keeping a diary. Feeling positive, accepting of what it is now. Feel my concerns were listened to and feelings were backed up by ARC information.

Clinicians spoke about the value of the ARC clinic's collaborative and coherent approach to meeting patients' supportive care needs. One CNS shared their thoughts on the impact of the ARC clinic in terms of offering the intervention alongside standard care, and at an underused point between initial and EOT in the cancer pathway:

> [The] ARC [clinic] has worked in collaboration very well with the specialist services. The additional support offered for patients at a specific point in their

> care enables the patient time to review and reflect on how things are and what is needed to further support their ongoing needs. Having this additional support to patients enhances their experiences at the trust and ensures all support options are available to them.

The ARC clinic enabled a marked increase in the number of HNAs and care plans being completed as well as the number of care plans being shared with GPs. Compared with routine initial HNA care plan completion rates of 13% (n=24) with 1.6% of those care plans being shared with GPs (n=7), the ARC clinic achieved 90% (n=46) with all care plans shared with GPs. Not only did the ARC clinic increase the number of HNA care plans being completed, but the quality of care was also improved, and the time required by CNSs to provide personalised care and support planning for the target patient group was reduced.

Lessons and limitations

From the outset, we identified potential problems and developed an iterative approach to making changes. We identified clinic space on two ICHT sites and set up the first clinic test run to problem-solve any identified limitations. The intervention was modified as it was implemented and after gathering user feedback.

Patient engagement

While we had identified a need for HNAs and care planning during the treatment phase, we were mindful that the ARC clinic was developed in the absence of an existing service structure that offered personalised care and support planning at this time point for people living with TbnC cancer. We acknowledged that offering an additional intervention (alongside standard treatment) and accessing patients at the identified intervention time point (6–24 months postdiagnosis) was also complex due to the unstable nature of advanced disease. In addition, we were uncertain around patient readiness to engage with an 'extra' intervention at a time point that is not well established. We monitored patient engagement and found the initial response rate and uptake to be low. At this point, we widened patient eligibility (from 6 to 9 months post-treatment) to include patients who were receiving care from ICHT on a TbnC cancer (breast, lung, colorectal and myeloma) pathway and were up to 24 months postdiagnosis; 55% of those contacted to take part felt the intervention was not needed.

Offering a new way of understanding adjustment and promoting self-management

The ARC clinic offered an opportunity for people living with TbnC cancer to raise their concerns, to identify personal goals and to be supported to achieve their goals. For staff, the ARC clinic offered new learning and capacity building in terms of providing support for personalised care and support planning.[38 39] This was echoed in patient feedback which confirmed that the ARC clinic process created a stronger basis in self-management—which is sometimes experienced as 'you're on your own'. The ARC clinic provided time to focus on individual needs and set goals, and to identify future rehabilitation opportunities. We were concerned that there might be a lack of onward services to meet identified needs and goals and so time was spent developing links and providing information sessions about the ARC clinic to rehabilitation services and across CNS teams. We found that stratifying and serving those whose needs were high was a strength of the project in terms of managing resources and staff capacity as well as considering future sustainability.

Emerging evidence suggests that telehealth has the potential to effectively address specific supportive care needs of people with cancer[40] and to produce outcomes superior to usual care for improving quality of life.[41] However, we identified challenges completing the follow-up HNA care plan review session by telephone. While remote healthcare offers opportunities, risks can also be posed in terms of privacy, trust and power relations between clinicians and patients, and influencing the overall quality of care.[42–44] Future research will focus on assessing remote health contributions to personalised care and explore how to improve the quality of collaborative digital care planning in cancer services. Research can also be expanded to include other tumour groups.

Measuring improvement

We were mindful that in terms of measurement, there is no existing system for tracking HNA outcomes, and that the ARC clinic database would need to be iteratively amended to capture meaningful data. In terms of continuous improvement and learning, we acknowledge the limitation of project funding for 12 months. While this allowed for time to develop, set up and pilot, it left little time to incorporate a continuous improvement approach such as PDSA.[45] Future research and improvement projects will build on the ARC clinic lessons to further understand how the ARC framework can be used to inform the codesign of interventions that better support personalised long-term cancer care.[46] The aim of the project was to design and test a new personalised care and support planning intervention to gather proof of concept. A future feasibility study will add value and go on to assess efficacy and effectiveness and to offer health economic analysis.

CONCLUSION

The ARC clinic offers an opportunity to coproduce personalised care and support for those who are living with TbnC cancer. To our knowledge, this is the first attempt to improve personalised care and support planning by developing an intervention underpinned by a conceptual framework developed from personal experience. Our future ambition is to extend the study beyond care planning and to consider digital personalised care interventions such as the electronic-HNA, virtual ARC clinics and online cancer recovery colleges.

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Contributors CLB provided support and oversight to the project and drafted the manuscript. JJ-J acquired funding, participated in the project design, provided oversight on study coordination, contributed to data collection, and drafted the manuscript. LJ coordinated the project, conducted data collection and reviewed the manuscript. AK is guarantor, acquired funding, participated in the project design, provided oversight on study coordination, contributed to data collection, led analysis and drafted the manuscript. SA contributed to drafting the manuscript. CU provided project oversight and reviewed the manuscript. All authors read and approved the final manuscript.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants the project was conducted as a quality improvement initiative. Approval was not obtained from an ethics committee. Participants gave informed consent to participate in the study before taking part.

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