

Personalised stratified follow-up after colorectal cancer treatment

Julie Lane and Tracey Becker present a report from an Association of Coloproctology Nurses interactive session

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Each year, the annual meeting of the Association of Coloproctology of Great Britain and Ireland (ACPGBI) provides an opportunity for members of the coloproctology community to meet one another, listen to inspiring clinicians and researchers and share their learning and experience with others within their national clinical network. Over the 3-day programme, the Association of Coloproctology Nurses (ACPN) provides a plenary session, short-paper session and an interactive workshop, open to all delegates.

In July 2022, the focus of the ACNP's 1-hour workshop was personalised stratified follow-up (PSFU) for people who have had colorectal cancer treatment. The aims of the session were to enhance the understanding of current approaches to patient follow-up after colorectal cancer treatment, support delegates to appraise their own criteria for assessment and decision-making relating to patient follow-up and to explore alternative perspectives and approaches with peers to inform an evaluation of practitioners' own practice.

Personalised stratified follow-up

PSFU is a person-centred approach that considers the interconnecting factors that affect an individual's health when making care decisions, based on the six components of personalised care (NHS England, 2019a). These components comprise shared decision-making; personalised care and support planning; enabling choice, including legal rights to choose; social prescribing and community-based support; supported self-management and personal health budgets and integrated personal budgets. Essentially, PSFU is about acknowledging the patient as a partner in their own care, genuinely valuing their perspective and preferences in making care decisions and supporting and protecting their autonomy within the process of care.

The ambition of the NHS Long Term Plan for England (NHS England, 2019a) was for all patients to have access to PSFU after colorectal cancer treatment from 2020. This replaced a historical follow-up pathway that was largely based on standardised and often service-centred processes, as well as clinical outcomes bluntly focused on surgical complications and cancer recurrence. PSFU is an adaptable pathway that suits patients' individual needs and ensures rapid access to specialist care and support delivered in line with the NHS Comprehensive Model for Personalised Care (NHS England, 2019b). PSFU is a vital part of delivering this model of care, and, at the end of 2020, PSFU protocols were in place in 62% of NHS Trusts in England (NHS England, 2022a).

This change in approach to follow-up has been driven by factors, including an increasing population of individuals living with and beyond cancer treatment who continue to have unmet needs, as evidenced by several patient surveys (Armes et al, 2009; Department of Health 2012; NHS England, 2021). As complexities of treatment modalities expand, both in surgical options for advanced or metastatic disease and oncological treatments tailored to individual tumour biology, potential side effects and consequences of treatment on quality of life broaden. Moreover, traditional scheduled outpatient appointments are costly and can be inconvenient for patients, as well as ineffective and anxiety-

provoking if delayed. Therefore, PSFU presents a timely alternative to traditional approaches to colorectal cancer follow-up.

The essential work completed by the National Cancer Survivorship Initiative (NCSI) has influenced the development of PSFU following treatment for colorectal cancer. PSFU is underpinned by the NCSI's vision for a cultural shift that focuses on wellbeing and patient experience, with care planning based on individual assessment, needs and preferences. The NCSI introduced the supportive self-management model to cancer care and highlighted the importance of the early identification and management of the consequences of treatment and implications for quality of life (NCSI, 2013).

Supporting interventions

The NCSI collaboration of NHS Improvement, Macmillan Cancer Care and the Department of Health investigated the needs of cancer survivors, working with 14 NHS organisations to design and test new interventions and models of care to improve the outcomes and experience of patients living with and beyond cancer (NCSI, 2013). These new interventions included holistic needs assessments (HNAs), treatment summaries, health and wellbeing events and cancer care reviews.

HNAs are tools that are used to structure meaningful conversations. They are questionnaires that can be completed on paper or electronically, independently by the patient away from a healthcare setting or with their healthcare professional. They aid the identification of patient concerns and needs across all aspects of their health and wellbeing, including physical, psychological, spiritual, practical and financial issues, from which personalised care and support plans can be developed (Macmillan Cancer Support, 2019).

Treatment summaries are a document shared with both the patient and the GP. They provide a record of the patient's diagnosis and recent phase of treatment. They detail possible side effects of treatment, signs and symptoms of recurrence and who to contact should these arise. If surveillance investigations have been agreed, then the timetable for these and any clinic appointments will also be recorded (NCSI, 2013). This aids communication between secondary care, primary care and the patient. A treatment summary can act as a prompt for a cancer care review. This is a conversation between the patient and their GP or practice nurse about their diagnosis, experience and concerns. Structured templates are available for health professionals to use to guide these conversations, which should take place within 3 months of a cancer diagnosis and within 12 months of completing a course of treatment. They are considered an important element of PSFU and are a quality outcome framework indicator, part of the GP contract to improve the quality of patient care (NHS England, 2022b).

The key principles of PSFU evolved from the work of the NCSI (*Box 1*). The language has been adapted to describe follow-up as an ongoing process that should be available to all from diagnosis and throughout their care pathway to recovery or transition to end-of-life care, as opposed to structured interventions focused on the completion of treatment and only for individuals with curative disease. For example, the 'recovery package' is now 'personalised care interventions'. Patients should be offered at least two choices of pathway (*Figure 1*), professional-led follow-up with scheduled appointments or supported self-management with remote monitoring. Professional led follow-up is not necessarily with a secondary care clinician, this can be undertaken within a primary care or palliative care setting. For some, the supported self-management option may be timely re-access to health professional review without any surveillance investigations.

Supported self-management

Patients on the supported self-management pathway take responsibility for recognising and managing any consequences of their cancer treatment. This includes adapting their lifestyle to improve their health and reduce their risk of recurrence, identifying signs of recurrent disease and deciding when and how to seek help from healthcare professionals (Howell et al, 2021). Any agreed surveillance investigations, including blood tests, colonoscopy and imaging, are arranged by the healthcare team, but these are managed remotely with no scheduled outpatient appointments.

For supported self-management to be successful, the key principles of PSFU need to be in place, and individual patients need to be empowered to self-manage (McCorkle et al, 2011; Zegler et al, 2022). This is reliant on effective assessment and care planning; supportive information with signposting to community-based services; and an open and transparent approach to communication from the point of diagnosis. Clear follow-up guidelines are necessary for the successful implementation of PSFU, which can be agreed by cancer networks or at a local level. Equally important is the process for managing abnormal results, those related both to colorectal cancer (such as elevated carcinoembryonic antigen (CEA) or signs of recurrence on CT imaging) and to the incidentalomas (such as renal adenomas or ovarian cysts). For many teams, these processes will include discussion at a multidisciplinary meeting and/or internal referral to other specialties for follow-up.

Supported self-management requires changes in practice, such as a greater focus on preparing the patient to self-manage from the point of diagnosis. Clinical teams need to be able to assess readiness for self-care and be prepared to relinquish control of the follow-up process to the patient. There may be a need for additional training in coaching skills and motivational imaging, and there is an increased reliance on digital systems (Howell et al, 2021). Digital systems are key to having a robust process that tracks patients' follow-up, ensuring that surveillance investigations are not missed and that results are communicated to the patient in a timely way. Digital systems can provide a platform for patients to access results, information and other resources, as well as communicate with healthcare professionals.

Workshop

At the ACPN workshop, delegates were presented a brief overview of the above context before being asked to reflect on and discuss in groups how colorectal cancer follow-up is structured and delivered within their own organisations and local services, using a set of guidance questions (*Box 2*). Case studies were then used to facilitate reflection on local services and personal practice.

Key areas of discussion stemming from the first activity included the difficulty in changing to a more holistic approach from a multidisciplinary team (MDT) focus on post-histology cancer staging as a key criterion in determining the follow-up pathway. Changing pathways when patients' needs alter was also felt to be difficult, although the clinical nurse specialist (CNS) was regarded as a key driver in follow-up pathway adaptation. MDT recommendations were considered to guide rather than determine decision-making, with shared decision-making with the patient being paramount. The timing of the clinical review to determine the follow-up pathway varied between delegates' organisations, depending on patients' individual treatment pathways and service structure. Follow-up with a CNS was often a precursor to supported self-management and remote monitoring.

For many, workforces are changing to facilitate the implementation of PSFU, including the introduction of the cancer support worker and navigator roles, as well as greater involvement of allied health professionals. Regional differences in community support services for financial advice, exercise and rehabilitation, support groups and psychological services were evident. Knowledge of what is available in each individual area was identified as essential for personalised care and support planning, to ensure availability of resources for those who wish to self manage.

The second workshop activity used case studies to facilitate discussion about personalising follow-up in practice. The central case study related to John (pseudonym), an 81-year-old man who presented through the 2-week-wait referral system with stage T3N2M0, not threatening the circumferential resection margin. John wished to avoid surgery and take a more conservative approach, and, as he was assessed as unsuitable for chemotherapy, he agreed to have radiotherapy, which generated an apparent complete response. Three main follow-up options of major surgery, intensive follow-up or no follow-up were offered; John selected intensive follow-up, which ultimately identified asymptomatic recurrence. In applying the principles of PSFU, John's case study generated discussion about the information presented to John: if he did not want surgery and was not suitable for chemotherapy, it raised the question of whether offering intensive follow-up was appropriate. Delegates explored whether the communication approach adopted at the contact points during John's treatment was truly personalised or influenced by professionals' reluctance to not act, highlighting a difficulty that many professionals can experience in the practice of PSFU.

Conclusion

PSFU is about acknowledging the patient as a partner in their own care, genuinely valuing their perspective and preferences in making care decisions and supporting and protecting their autonomy within the process of care. The ACPN workshop enabled delegates to gain greater understanding of the theory and practice of PSFU and provided an opportunity to reflect on their own role, the challenges they may encounter in adopting PSFU and ways to enhance PSFU within their own service organisation and delivery.

For information about ACPN or to enquire about joining, contact Nicole Taub (ntaub@acpgbi.org.uk) or Chair Gabby Thorpe (gabrielle.thorpe@uea.ac.uk). [GN](#)

Box 1. Key principles of personalised stratified follow-up (NHS England and NHS Improvement, 2020)

- Ensure choice of follow-up pathway is a shared decision between the person living with and beyond cancer and the clinician
- Offer personalised care and support planning (based on holistic needs assessment) at key points in the pathway
- Provide end-of-treatment summaries to people living with and beyond cancer and their GPs
- Guarantee timely access to appropriate professionals
- Ensure information, advice and support (from diagnosis) is tailored to individual needs, knowledge, skills and confidence and that it supports wider health and wellbeing
- Enable surveillance tests and scans to be monitored remotely via digital systems
- Provide seamless, personalised, coordinated care through cross-organisational working
- Support people living with and beyond cancer, where able, to take responsibility for optimising future health and wellbeing
- Optimise workforce skillmix, such as using support workers to help release clinical nurse specialist time for complex patients

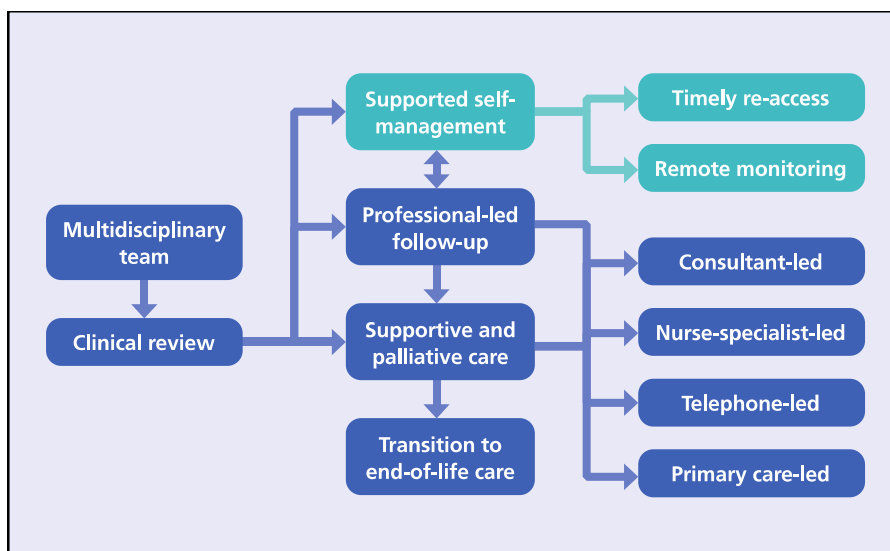


Figure 1. Personalised stratified follow-up pathways (NHS Improvement, 2016)

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