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Follow-up care in cancer: adjusting for referral targets and extending choice

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Abstract

Background Over recent years, several initiatives have impacted on the referral of patients to secondary care, most notably targets for urgent referral in suspected cancer and the patient choice agenda. At the same time, improved long-term survival in cancer has increased numbers attending follow-up, doubts about the effectiveness of specialist follow-up have emerged, and alternative models of follow-up have been tested.

Aim The aim of the study was to explore patient and carer perspectives on the flexibility and responsiveness of cancer services. This article focuses on findings relating to referral, subsequent outpatient appointments and cessation of outpatient follow-up.

Methods Issues were explored in a qualitative study using face-to-face interviews with a purposive sample of 54 people affected by cancer. Data were analysed concurrently with data collection, using qualitative analysis software.

Findings The study gave rise to a number of salient themes. Links were identified between three of these: choice and responsiveness during referral; the flexibility and responsiveness of outpatient appointment systems; and negotiating cessation of follow-up. It appeared that policy on urgent referrals might be adversely affecting practice relating to appointment systems and the continuance of follow-up.

Discussion and conclusions Hospital-based cancer follow-up is being given decreasing priority because of doubts about effectiveness and a target-driven focus on referral. This is impacting on patients, who may value outpatient follow-up as a 'safety net' but have difficulties in obtaining appointments, and may be discharged without negotiation or adequate support. For these reasons, new forms of flexible/responsive aftercare are urgently needed.

Background

This article is concerned with appointments for outpatient consultations in both the diagnosis and follow-up phases of cancer. It arises from a wider study of patient/carer perspectives on the flexibility and responsiveness of cancer services to their preferences and needs. Relevant findings from the study are discussed with reference to the recent emphasis on referral targets, patient choice, responsive and personalized health care, and management of chronic illness within the National Health Service.

Referral for diagnosis

Over the past decade, a number of initiatives have impacted on the referral of patients from primary to secondary care. The most notable of these have been national targets for urgent referral in suspected cancer and the drive to provide patient choice at the point of referral.

The national targets were introduced from 1999 onwards, backed up by referral guidelines for general practitioners (GPs).[1–3] The target wait for those referred urgently was set at 2 weeks. Although there is evidence to suggest that, subsequently, waiting times for these patients decreased,[4,5] there has been much debate about the unintended consequences and failures of the targets/guidelines including reports that about 27–58% of those diagnosed with cancer were being referred via the non-urgent route[6,7] and that waiting times for non-urgent referrals had increased.[6,8] These reports are mainly based on audit/case-note review and do not feature the perspectives of people diagnosed with cancer. From January 2010, possibly prompted by some of this evidence, all patients referred with breast symptoms must be seen within two weeks.[9] In 2006, guidance was issued on integrating urgent referrals into Choose and Book,[10,11] a scheme designed to allow all patients a choice of hospital, and appointment date/time.

Follow-up

Whilst conducting an initial literature review,[12,13] we noted that Government policy had concentrated on choice in relation to referral/diagnosis, and place of death[14,15] and that the follow-up period in general featured little in the Cancer Plan[16] and a subsequent progress report.[15] The review also highlighted a lack of relevant research literature; issues such as choice and decision making had mainly been studied with reference to initial treatment[17] and the end of life.[18] In addition, a later search identified a lack of research into patients' experiences of hospital follow-up appointment systems.

In recent years, long-term survival has improved so that, in some instances and ways, cancer can now be viewed as a chronic illness.[19] Debate about the effectiveness of routine, technologized hospital follow-up to detect recurrence and increase survival has been on-going since the mid-1990s, and some authors have questioned whether patients treated for cancer need to be followed up at all.[20] Other publications highlight the likelihood that the importance, length and nature of follow-up will vary with cancer type/site, treatment modality and stage of disease.[21–23] In the light of such evidence, guidance on a range of cancers has been produced, which tends to recommend that specialist follow-up should be time-limited.[24–26] For example, for recurrence-free patients, specialist breast cancer follow-up 'should cease' at 3 years.[24]

Research publications highlighted in our initial review[12] address concerns of importance to patients during the follow-up period, such as attention to psychosocial issues, self-reported symptoms and persisting needs,[27–32] reassurance,[28,29,31,32] continuity,[27,29,30,32] and allowing time.[27,32] Many of these suggest that, while patients fear being 'abandoned' at the end of hospital follow-up,[27,29,31] their concerns are often inadequately met during consultations, an issue also identified in more recent studies.[33,34] There have been numerous intervention studies on alternatives, such as patient-initiated, risk-adapted and telephone follow-up, and follow-up by nurses or GPs,[35–40] some of which fail to mention patient perspectives and preferences.[37,38]

Aims

The findings reported in this article derive from a wide-ranging study designed to explore patient and carer experiences of and views on the flexibility of cancer services and their responsiveness to patient/carer preferences and needs during the diagnosis, treatment and follow-up phases of cancer.[41] The article itself focuses on findings relating to initial referral, subsequent outpatient appointments and cessation of outpatient follow-up.

Methods

The issues above were explored in a qualitative study influenced by grounded theory methods.[42]

Sampling and access

Purposive sampling[43] was used to achieve a broad sample composition. Recruitment was achieved via:

1. A regional cancer centre (RCC) and a non-teaching acute trust in North-west England. Participants were identified and approached by clinical nurse specialists (CNSs).
2. Contacts in support/self-help groups for cancer in North-west England.

Clinical nurse specialists and support group contacts used inclusion criteria (Box 1) to identify potential participants and gave those who showed initial interest an information pack. This explained that we also wished to interview the patient's main carer, if both parties agreed, and a carer information sheet was enclosed. Carers' perspectives were sought because they may carry a heavy burden of care and need support from services.[44,45]

Box 1 Study inclusion criteria

Patients were included if they:
- Were aged 18 years or over;
- Were at least 12 weeks post-diagnosis (to allow some time to come to terms with the diagnosis and experience a range of services);
- Had a secure diagnosis and were fully aware of this;
- Either had no evident active disease or were living with cancer;
- Were not in the end-of-life phase

Interviews

In-depth digitally recorded interviews were conducted between May 2006 and January 2007 by two experienced interviewers (KW and AL). They were conversational in style, and a flexible interview guide encouraged participants to influence the agenda. The preliminary researcher-generated topics for discussion are presented in Box 2.

Data organization and analysis

Data analysis was conducted concurrently with data collection and, consistent with a grounded theory approach, affected development of the interview guide and thus the issues pursued. Deeper levels of analysis extended beyond the data collection period. The recorded interviews

Box 2 Preliminary topics for discussion – original interview guide

Services experienced during diagnosis, treatment and follow-up;
Examples of services that have been particularly flexible in their ways of working and/or responsive to preferences, needs and requests;
Examples of services that have been inflexible and not responsive to preferences, needs and requests;
Ways in which other services could learn from the flexible/responsive service(s) described;
Issues/situations that prompt a need for flexibility and responsiveness on the part of services;
Ease/difficulty of expressing preferences and needs to health and social care professionals;
Involvement in schemes or organizations designed to increase patient/carer participation and self-determination;
Innovations that might help patients/carers express their preferences and needs and/or make services more flexible and responsive;
Any other relevant issues participants want to discuss.

were transcribed, and the data were entered into the ATLAS.ti qualitative analysis package. Transcripts were read to gain an overall sense of meaning and, as the number of transcripts grew, identification of common themes and links between themes commenced. Contextual notes were also considered during analysis. Most transcripts were analysed by one researcher (KW), but AL co-coded a proportion independently and differences in interpretation were discussed and resolved.

Towards the end of analysis, anonymized data were discussed at an advisory group meeting in order to enhance the credibility of interpretation and, thus, the rigour of the research.[46] The advisory group included two service users, who also commented on draft reports.

The wide-ranging remit of the overall study made data saturation[42] difficult; further to this, Morse suggests that saturation may be an indefinable/unachievable goal.[47,48] Data collection/analysis ceased when the researchers agreed that the aims of the study had been largely met.

Ethical issues

Approval was obtained from a local research ethics committee. Written consent was obtained from all participants. Each patient and carer were given a code (e.g. P1, C2) for use in recordings, transcripts and reports in order to maintain confidentiality.

Findings

The overall study gave rise to a number of salient themes including the flexibility/responsiveness of CNSs and the variety of preferences relating to continuity. Links were identified between three prominent themes: choice and responsiveness during referral for diagnosis; the flexibility and responsiveness of outpatient appointment systems; and negotiating cessation of follow-up. This paper focuses on patient/carer experiences and views of the early and later stages of the cancer journey because it was recognized that policy on the former may be adversely affecting practice during the latter. Treatment-related policies and practice did not appear to be having a similar impact on other phases of the trajectory.

Data on experiences of referral relate to patients diagnosed in the two years prior to interview; data on outpatient appointment systems and cessation of follow-up include experiences from the past two years and, where relevant, a historical perspective from those who had experienced follow-up for up to 15 years. Demographic details are presented, followed by findings relevant to these themes.

Demographic data

Thirty-eight patients (14 men and 24 women), and 26 carers (11 men and 15 women) were interviewed. The demographic characteristics of patients and the sources from which they were recruited are presented in Box 3.

Experiences and views of choice at referral

In general, participants were not aware of being offered a choice of hospital and appointment date/time at referral. Only P31, diagnosed with oesophageal cancer in 2006, experienced a choice between two local hospitals. She rejected the nearest, saying that she would not send her 'worst enemy' there, and chose the other based on personal experience, stating that it provided a model because 'as well as meeting the medical needs, they're meeting the patient needs'.

There were numerous comments about the appropriateness of offering patients a choice of hospital, including from P5 who said she would probably choose one nearby because it would be easier for visitors. However, she added 'I'm making that choice on the logistics, which don't matter a hoot really in the long run'. Other participants noted that, as implied by P5, people might regret the choices they made:

Box 3 Demographic characteristics of patients (n = 38) and relationships of carers (n = 26) with patients

Gender	Numbers
Male	14
Female	24
Total	38
Age	
30–39 years	2
40–49 years	2
50–59 years	12
60–69 years	16
70–79 years	6
Total	38
Time from diagnosis at interview	
3–6 months	9
6 months–1 year	9
1–2 years	6
2–3 years	2
3–4 years	1
4–5 years	2
5–10 years	7
> 10 years	6
Total	42*
Cancer type ⁄ site	
Gynaecological	8
Breast	6
Haematological	5
Upper gastrointestinal	5
Prostate	4
Colorectal	4
Lung	2
Pancreas	2
Sarcoma	2
Unknown primary	2
Peritoneum	1
Thyroid	1
Total	42*
Recruitment source	
Acute trust	6
Regional cancer centre	21
Support group	11
Total	38
Carer relationship	
Wife	11
Husband	11
Daughter	3
Mother	1
Total	26

*Four patients had experienced two separate cancers.

> If you… discover actually that another unit would have had more expertise or more high-tech equipment… and things go wrong... then the consequences of that are… you feel bad. (P6)

Further to this, P5 was grateful that her doctor had referred her to a surgeon 'with an international reputation' and echoed other participants by saying that choice at referral was not appropriate because patients did not have the necessary knowledge or emotional resources:

> I wouldn't want to have to choose... I don't want to have to do homework. I don't want to be given comparative lists… because you just can't handle it... You're in turmoil. (P5)

When asked whether patient choice and competition between hospitals might improve standards, participants were often sceptical and commented that wards and hospitals were being closed, services were being cut and access to certain treatments was being restricted, actions that removed or reduced choice. Further to this, P1 asserted that the patient choice agenda was 'a financial thing... not a patient-driven thing'.

Experiences of and views on urgent and non-urgent referral

The system for urgent referrals sometimes worked well. For example, in 2006, P13 experienced rectal bleeding and was immediately referred to hospital by his GP. He was seen within two weeks and quickly diagnosed with colorectal cancer. P20, who had a strong family history of cancer, had a different experience when she consulted her GP about worsening abdominal discomfort in 2004:

> He said '…I don't really think there's a problem there, apart from irritable bowel, but I'll make you an appointment, but it will be a non-urgent appointment'. (P20)

P20 waited three months for an appointment and a further 10 weeks for a colonoscopy before being admitted with a bowel obstruction. She did not blame her GP for making a non-urgent referral, in view of her pre-existing irritable bowel condition; certain other patients also felt it reasonable that they were not referred urgently.

However, participants were sometimes distressed about delayed and non-urgent referral. P37, diagnosed with breast cancer in 2006, 'felt really angry' that her GP delayed for three months and then made a non-urgent referral; she waited four months for her first appointment. P31, who experienced earache, dysphagia and swollen glands, saw two GPs before a third, at her insistence, made a hospital referral. She discovered that this was a non-urgent referral and consulted yet another GP who 'listened' and made an urgent referral. Nine days later, six months after her first GP consultation, she was diagnosed with oesophageal cancer. Participants also reported that urgent referrals sometimes failed because they were made on the wrong form or went missing.

The aforementioned examples relate to local hospitals; patients were typically referred to these for diagnosis and surgery, following which some attended the RCC or a local cancer unit for chemotherapy, radiotherapy and/or other adjuvant treatment.

Experiences and views of outpatient appointment systems

After treatment, patients entered outpatient follow-up. Some experienced no difficulty in booking and/or receiving appointments, especially at the RCC. When patients booked appointments in person, usually at the end of a consultation, test or inpatient stay, they were able to negotiate the time and date and left the hospital with a feeling of certainty. However, inflexible and unresponsive appointment systems were encountered at some hospitals:

> [At Hospital J] they say, 'Oh, we'll send it out in the post'... [At the RCC] it's put on your card... They arrange them six months apart, twelve months apart! But they can't book that far in advance [at Hospital J]... Why can't they do it there and then? Put it on a card and say, '… There's your appointment'. (P34)

> The only criticism I have, not with [Consultant T] himself, but of the appointment system, is that [Consultant T says] 'I'll see you in three months' and three months goes by and nothing happens. You ring up: 'I should have seen [Consultant T]'. 'Well, he's very busy'. And I said, 'It's not my problem that he's very busy. He wants to see me'. (P19)

P19 and his wife were vocal critics of the appointments system; C19 commented that patients could not make a 3-month appointment before leaving the hospital after a follow-up visit because 'the computer only does it for up to 2 months'. She had also been told that there was 'a capacity problem' with Consultant T's clinics, leading P19 to wonder whether the computer was being used as an excuse 'because they've got too many people for slots'. He commented that the appointments system was 'the most annoying thing' he had experienced during his encounters with services for cancer.

Participants said that they had had to be 'pushy' (P12) or 'bolshy' (C15) to get an appointment. There were reports that appointment systems used to be flexible/responsive but had deteriorated. P8 who had been attending follow-up for almost 10 years had noted this latterly:

> The appointment follow-up system has absolutely gone to pot. It was really, really good at first... [Consultant R] would say 'I'll see you in three months', and you went to the desk and they arranged an appointment… and that appointment never changed. But... for the past maybe two or three years: Oh my goodness me! I can get six letters that's telling me this appointment has changed. And… instead of the appointment being made there and then at clinic, it's 'Oh, you will hear'. And you don't hear. And if I didn't keep a track of it, my last appointment would just totally disappear into the ether somewhere. And I had to phone and phone and phone and phone and, eventually, I got a clinic appointment. (P8)

Participants also commented that they did not know whom to contact when trying to obtain an appointment, although several described experiences of telephoning clerks/receptionists and consultants' secretaries, some of whom responded helpfully. P7 found that the absence of a particular staff member and/or staff shortages was given as reasons for inability to respond:

> He [the consultant] says, 'Now, I'll see you in three months' time'... I did ring up, because it's over three months now… and I was told… 'His secretary has left. We're way behind'. So I thought, 'Surely the hospital doesn't stop just because one person's left'. (P7)

This lack of response was particularly galling to P7 as he was dissatisfied with the support he was receiving from his GP practice. Disregard for individual patients' circumstances and a lack of personalization could occur in patients living with cancer as well as those without evident active disease. P22 had liver metastases, but the primary cancer had not been found and treatment options had not been discussed. He and his wife were distressed when his next appointment was suddenly postponed for four months 'due to lack of doctors' (C22). On contacting the clinic, C22 found that all appointments had been moved '*en bloc*' to the later date. She commented that a less assertive and knowledgeable person might have thought 'It can't be that bad then. They don't want to see me'. Other participants made similar comments, including P24 whose 'meek and mild' neighbour 'had just let them move appointments' and had recently died of cancer at an early age.

Although patients were keen to obtain a follow-up appointment, in some cases this may have mainly been because their consultant had specified a time interval (see the quotation from P19 above). Participants generally expected to see a doctor at appointments, although those who always or sometimes saw their CNS were happy with this, as it could provide continuity rather than brief contact with a succession of (usually junior) doctors. There were also comments that clinics were so busy that patients felt 'under pressure to be seen and got out of the way' (P12) and therefore often failed to ask questions. Thus, although outpatient appointments generally provided a degree of reassurance, informational and psycho-emotional needs were not always met.

Experiences and views of discharge from outpatient follow-up

Some patients had been given a clear schedule when entering follow-up, but there were no instances of schedules arising from negotiation between patients and health professionals. For instance, P19 was told 'this is what will happen':

> I've three-monthly appointments with [Consultant T] for twelve months, and then six-monthly appointments for the next twelve months... And then, depending on the results, I shall then go to the GP. (P19)

P19 seemed content with this plan. Two participants who had been diagnosed with breast cancer more than 10 years previously were also satisfied with follow-up arrangements: they were both told they would receive specialist follow-up for life. However, during recent years, there had been moves to discharge them:

> With all the numbers they're dealing with, they're saying, 'Well, we can discharge you now', and I said 'No you won't!'… I refused, and they were quite happy with that… It also came up [again] last year… Last year coincided with the debacle at [Hospital D], with which a close friend of mine was involved: she's now terminally ill. It also coincided with another close friend… She had breast cancer after me and something's gone wrong there and she's also terminally ill… Removing my yearly check-ups was not somewhere I was happy to go... I had a check-up last week and it was me who then said, 'Look, I think I can stop now' and they were good then because he [doctor] said, '[If you have] any questions you can come straight back. Just make a phone call…' I was in a slightly different place this year from last year, and that was because of external stuff happening… that made me feel insecure… I think if you say to a patient, 'You will be looked after and be checked annually… for the rest of your life' then you stay with that. (P6)

P6 regarded follow-up as her 'mental safety net'. Although the doctors tried to discharge her without acknowledging that they were reneging on an agreement and without discussing how she felt about this, they responded positively to her objections. Her decision to stop attending was attributable to knowing people who 'have coped with it on a much shorter timescale' and a feeling that recurrence was unlikely.

P10 was also approached about ending follow-up at a bad time, as she had some worrying symptoms. The junior doctor she saw in outpatients dismissed her concerns and quickly turned to trying to discharge her:

> He said, 'Now, after 12 years, we'll discharge you'. So I said, 'I'm very sorry, I'm happy to be discharged but I want a mammogram'. [He said]

> 'Well, we don't do a mammogram'… He was very adamant that I wasn't going to have one and I was equally adamant that I was! And then he said to me it wasn't going to show up anything and 'I'll get into trouble giving you a mammogram when it's not required'. So I said, 'If you get in trouble, would you like to refer me to [consultant U] and I'll… tell him that I am not happy about not having one'... I know a mammogram costs money, but I said… 'There's no point in me going home and my GPs trying to get to the bottom of it… If my doctor doesn't find anything, he's going to refer me back... So why don't we do it now?' I don't think it was very well received, actually. He did give way. (P10)

P10 was happy to be discharged after a mammogram because she had the 'luxury of a very good GP' but was concerned about patients who did not have that 'luxury' and/or were not assertive:

> If I was that type of person I would've gone away worrying… [I know that from] talking to other people that's been in this circumstance [who said]: 'Well I didn't like to ask or I didn't like to say'. (P10)

The cases of P6 and P10 show that expectations, timing, the effects of wider events, available support and responsiveness to patient concerns are important factors in whether discharge from outpatient follow-up is acceptable. They also provide examples of patients being assertive and getting the desired response.

P1 had been followed up for mild leukaemia for over 10 years; follow-up consisted of an annual blood test and consultation. He had tried to discharge himself because he felt 'a bit of a fraud' and wondered if he was 'taking somebody else's time up', but the doctors wanted him to continue. It appears that patients were not expected to exert choice or negotiate about discharge from follow-up. It is also clear that resources and the needs of other patients were in participants' minds when contemplating discharge.

Discussion

As with all qualitative research, the findings of this study are not generalizable, but readers may find them applicable to their own experience and/or practice. The study was conducted in one English region and may have varying degrees of relevance to other regions of the UK.

The findings suggest that policies designed to improve referral from primary to secondary care[1–3,10,14] may have had little positive effect, in terms of both access to urgent referral and choice of hospital, on the experiences of people subsequently diagnosed with cancer. Moreover, it became evident that participants were not confident about making choices at referral because of emotional turmoil and limited knowledge. Participants valued outpatient follow-up as a 'safety net', but there were reports that the system for obtaining appointments had become less flexible and responsive over recent years. There were also attempts to discharge patients from follow-up without negotiation.

Thus, participants experienced a distressing lack of responsiveness in relation to both urgent referral and follow-up appointments; they did not wish to make choices at referral but complained about a lack of responsiveness and negotiation during follow-up. Below, we explore these findings and the possible links between them in more detail.

The impact of referral targets

The issue of urgent/non-urgent referral to secondary care was prominent in the interviews and crucial to some participants. Although some were referred urgently and seen promptly, others reported difficulties such as not knowing whether they had been referred urgently, not being referred urgently but feeling that they should have been and system failure. The debate about the intended and unintended consequences of the two-week wait target has included suggestions that the GP referral guidelines are not fit for purpose and, far from supporting GPs, may de-skill them.[6] This may have led to the recent decision that all patients with breast symptoms must be seen within 2 weeks,[9] a new target that will have major consequences for the capacity of breast clinics. Other specialities may have to meet a similar requirement in future, as breast cancer is often the leader in policy and guidance matters.[1,24]

The patient centredness of choice at referral

At the time of data collection, Choose and Book[10] was in its infancy, and it appeared that participants had not encountered it or, by and large, other facets of the Government's choice agenda. Research and other literature suggests that implementation of Choose and Book has been slow and problematic.[49,50] However, participants in our study did not welcome having to make a choice at the point of referral, feeling that they lacked the knowledge and emotional resources to do so and showing scepticism about the Government's motives for introducing patient choice. A reluctance to take responsibility for decision making early in the cancer journey and a desire to be more participative at a later date have been noted before.[51] Questions about the patient centredness of the UK choice agenda have also been raised previously.[13,52,53]

Referral targets vs. follow-up appointments

The issue of inflexible and unresponsive outpatient appointment systems was one of the most important and unexpected emergent themes and is a topic that has received little research attention.

Outpatient appointment systems at general hospitals were a mystery to many service users. Participants were highly sceptical about the explanations given by members of staff for being unable to offer an appointment and sometimes regarded them as excuses. It seemed that some patients were effectively being denied follow-up by a confusing and unresponsive system. Comments about the deterioration in appointment systems over recent years invite speculation about the cause. It seems possible that waiting list targets have had an impact, with doctors needing to give priority to consultations with new patients. Potter *et al.*[6] state that, in the hospital where they undertook their study on urgent/non-urgent referral, follow-up procedures were formally modified to create greater clinic capacity. Our data suggest that informal ways of creating capacity may also be at work; inability to make an appointment in person and serial postponement could both be used in this way. Further to this, Wong and Chow[27] note that patients are sometimes unsure about whether follow-up is tailored to their clinical need or dictated by resources.

Discharge from follow-up without choice or negotiation

The need to reform cancer follow-up because of the sheer numbers of survivors[20] has been intensified by an increased emphasis on rapid referral in suspected cancer.[6,9] The moral case for reform is supported by evidence suggesting that, in at least some cancers, follow-up clinics serve the purpose of reassuring patients rather than detecting recurrence.[54]

However, despite a large body of research on alternatives to traditional hospital follow-up, our data suggest that some patients are being discharged without being offered a formal alternative (or a choice of alternatives), such as nurse-led or telephone follow-up.[39] This is even the case with those promised lifelong follow-up. Our data also illustrate that discharge was not treated as a matter for choice or negotiation (although assertive patients felt able to refuse, and/or negotiate terms). This is despite evidence that the further patients are from the time of diagnosis, the more likely they are to want to participate in choices about their care.[51]

The discharged patients in our study had competent, accessible and supportive GPs but noted that not everyone has this advantage. Other studies have highlighted patients' reservations about GP-led care after cancer.[55–57] These include a lack of rapport, time and specialist knowledge.[56] Whether GPs are well-prepared and recognize cancer follow-up as an increasing part of their role, and whether patients are receiving adequate preparation for survivorship is unclear. If not, there is the danger of producing a cohort of unsupported patients who feel they are being neglected or abandoned for purely resource-related reasons and who may develop cancer-related physical and psychosocial problems. This may be particularly so with patients who are unwilling to consult their GP about cancer because they have experienced late/non-urgent referral, as reported in our findings.

Given that reform of follow-up already seems to be happening informally, through earlier discharge and/or inability to obtain outpatient appointments, and that pressures on outpatient clinics are likely to increase, the introduction of formal alternatives seems timely.

From follow-up to aftercare

The National Cancer Survivorship Initiative (NCSI)[58] is proposing a model of 'personalized aftercare' which draws on recent approaches to the management of chronic illness,[59,60] and aims to limit long-term physical, emotional and vocational consequences of cancer and its treatment. It consists of a post-treatment assessment and care planning followed by supported self-management, with rapid re-entry to specialist services if necessary. Need for specialist and other services will be co-ordinated by a case manager. Whether patients will be able to choose a preferred member/type of staff, such as a CNS, as their case manager is unclear.

As the low priority now afforded to traditional follow-up is impacting on patients, it is important to implement the NCSI, or similar, aftercare model as soon as possible. Although our data raise some questions about the acceptability of non-specialist aftercare, as time goes by and people 'grow up' with the new model, memories of traditional follow-up will fade and expectations may alter.[55] Until this happens, it may be necessary to continue specialist input with older patients and those already given assurances of lifelong follow-up. While Beaver *et al.*[39] found higher satisfaction with CNS-led telephone follow-up than traditional follow-up amongst participants in their trial, 40% of those approached declined to participate because of a preference for face-to-face contact, a wish for clinical examination or family members' concerns about being excluded. Education about the ineffectiveness of traditional follow-up might change perceptions,[55,56] but sensitivity will be needed as this information could provoke anxiety.

The term 'personalized aftercare' invites consideration of differences between 'personalized medicine' and 'personalized care'. Whereas the former is a medically centred approach based on risk, the latter can be seen as a patient-centred approach based on preference. It will be important, when planning aftercare, to ensure that risk of psychological morbidity is assessed[61] and to acknowledge that whether patient preferences are met may impact on psycho-emotional health. Outcomes may be poor in patients who are given no choice and feel that they have been abandoned for resource-driven reasons. Lastly, in addition to the *caveat* above about existing and older patients, those who are not confident and proactive may find it difficult to engage in supported self-management 'in which the active participation of cancer survivors is crucial'.[58] However, our data support other studies in suggesting that difficulties with raising concerns and asking questions also occur within busy outpatient clinics.[27,28,33]

Conclusions and implications

Traditional hospital-based cancer follow-up is being given decreasing priority, because of doubts about its effectiveness and a target-driven focus on new referrals. This has begun to impact on the experiences of patients, who may still value outpatient follow-up as a 'safety net' but may have difficulties in obtaining appointments and are at risk of being discharged without negotiation or adequate alternative support. For these reasons, new forms of flexible and responsive aftercare are urgently needed.

However, research into the acceptability and effectiveness of forms of aftercare is still needed; the NCSI are evaluating personalized care plans, supportive self-management and psychosocial support in 'test communities' throughout England and Wales. Further research may be needed into models of aftercare in primary care and into improving appointment systems, care planning and personalized support for those who choose or, because of clinical factors, need to stay within the hospital system.

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Conflicts of interest

No conflicts of interest.

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