

**Perspectives of patients with haematological cancer on how
clinicians meet their information needs: ‘managing’ information
versus ‘giving’ it**

Running title:

Managing information for patients with haematological cancer

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ABSTRACT

Objectives

Practitioners treating patients with haematological cancers have extensive clinical information available to give to patients, and patients need to be informed. However, many patients want to be protected from having information that is too detailed or threatening. To illuminate how practitioners can address this dilemma and help patients feel appropriately informed, we explored patients' experience of feeling informed or uninformed.

Methods

Semi-structured interviews were conducted with 20 patients who had been diagnosed with haematological cancer and had recently received results from clinical investigations or from evaluations of treatment response. Inductive and interpretive analysis of the transcribed audio-recorded interviews drew on constant comparison.

Results

Patients described the need for practitioners carefully to manage the information that they provided, and many felt alarmed by information that they did not experience as having been managed for them. A few patients who had difficulty trusting practitioners were not content with the information provided.

Conclusions

These findings can be understood using attachment theory, whereby practitioners' careful management of information demonstrates their care for patients, and patients' trust in the practitioner enables them to feel informed. It follows that, when patients do not feel informed, the solution will not necessarily be more information, but might be to help patients feel more secure in a caring clinical relationship.

KEYWORDS

Cancer; haematological oncology; information needs; attachment; clinical relationship; qualitative.

1 BACKGROUND

Haematological cancers account for 7-9% of oncology cases in developed countries and a similar proportion of cancer-related deaths(1,2,3). They are psychologically challenging(4) and patients face uncertainties throughout their illness. The course of disease is often unpredictable; conditions can evolve with time, and treatments need to be initiated or modified in response to changing clinical behaviour(5). Treatment options range from ‘watchful waiting’ to chemotherapy and stem cell transplantation, and can be unpleasant and hard to adhere to(1,2). Treatment decisions are dictated by complex clinical information from frequent assessments, including blood tests and imaging(1,2).

While health policy has long recognized that patients should have information that allows them to be involved in treatment decisions(6,7,8), it can be unclear what this means in practice. Some guidance encourages cancer practitioners to provide ‘all available information’(9). This is often unrealistic, where more information is available than could be relayed in practice. Besides, there is evidence in cancer populations including haematological cancers that patients want protection from detailed or threatening information(10-14). Practitioners are therefore sometimes guided to give patients ‘the information they want’, but this also can be unrealistic where patients cannot know the extent and nature of available information(9).

Haematological cancer patients’ own perspectives on receiving information from practitioners might inform more realistic guidance, but existing literature is contradictory. Reviews have concluded that patients were generally satisfied with information, despite often not knowing important details of their illness and treatment(15,16,17), and that they were more likely to feel informed if they trusted their practitioners(17). The aim of the present study was to explore patients’ experience of feeling informed or uninformed, in order to understand how practitioners can help them feel appropriately informed. Our aims were inductive; that is, we wanted to develop new ideas in a field in which existing ideas are limited. Therefore our approach was qualitative.

2 METHOD

2.1 Sample and recruitment

Purposive sampling included patients aged ≥ 18 years, diagnosed with haematological cancers and attending routine treatment and follow-up clinics in a specialist haematology service at a university teaching hospital from August 2014-April 2015. In their most recent ('index') consultation, patients received information from investigations or tests to inform diagnosis or treatment decisions or indicate treatment response. Index consultations were with consultants, specialist trainees in haematology, or a senior pharmacist in the haematology team (denoted generically as 'practitioners' henceforth). The practitioner that patients saw at any consultation depended on their needs at the time; patients therefore encountered several members of the team over time.

After ethical approval (13/NW/0865), a practitioner introduced the research to suitable patients during the index consultation. Maximum variation sampling entailed asking practitioners to select patients across a range of diagnoses, prognoses, treatment stage, gender and age seen in the clinic. Socio-demographic details including highest educational qualification and type of occupation were recorded to confirm variability in these characteristics also. Interested patients met the researcher (KA), who provided written information, reassured patients of her independence from the clinical team, explained that participation would not influence care and sought written consent. Patients were excluded if they were on palliative pathways or considered too distressed or unwell to consent. We recruited in parallel with analysis until judging that theoretical saturation was reached; i.e. new data did not modify the analysis.

2.2 Data collection

The researcher (trainee clinical psychologist with five years' experience of research and clinical interviewing) interviewed consenting patients in a private room in the clinic or in patients' homes, as each patient chose. Interviews were semi-structured and conversational, using open questions and reflection to facilitate talk, and closed questions to probe specific points. Using an interview guide, KA prompted patients specifically about: what information they received in the index consultation and on other key occasions and what it meant to them; and what significance the information had for

informing treatment or other decisions or for their lives more broadly. The guide was revised in line with ongoing analysis to explore emerging findings. The researcher kept field-notes to record contextual information and reflexive observations. Interviews were audio-recorded, then transcribed, excluding identifying details. Transcript extracts illustrate categories of the analysis below. Ellipses and square brackets indicate omitted and explanatory text, respectively.

2.3 Data analysis

Analysis drew on a pluralist qualitative approach, in which we sought ‘methodological integrity’ by adopting practices that ensured fidelity to the data and utility for the research question(18). Three authors (KA,BY,PS) read and discussed in detail the first five transcripts and associated field-notes to identify, as a starting point, features that were salient in the data and any that, given the context, were noticeably absent. Then KA led analysis in regular discussion with BY and PS, each of whom read all transcripts, and periodic discussion with NK who read selected transcripts. We used Microsoft Word to label and organize text using inductive headings that evolved over the analysis(19). Following a constant comparison approach(20), the developing analysis was tested and elaborated by reading and discussing additional transcripts as they became available. Differences of interpretation during discussions alerted the team to competing explanations, and identifying discrepant cases helped test and develop the analysis. The team included psychologists with research and clinical experience in psychological adjustment to cancer and in clinical communication, and a consultant haematologist with research experience in lymphoid malignancies. Some authors had family experience of haematological cancers. We drew on these different perspectives as sources of alternative interpretations of data. We considered transcripts descriptively at first, with an interpretive approach then developing whereby we considered meaning of text in the context of each interview as a whole and the emerging analysis(21). We continually judged analysis according to consensus validity (through debate, it should satisfy all authors;22), reflexive validity (it should change authors’ initial and subsequent views;22), catalytic validity (it should have potential practice implications;22,23), and theoretical validity (it should have implications for theory;23). In presenting the final analysis, below, we describe salient recurrent or variant features of participants’ accounts, and our interpretation of

how these are linked(24). It is in the context of that ‘interpretive explanation’ that those features gain relevance to research question(25).

3 FINDINGS

3.1 Sample characteristics

Four patients declined participation after seeing the researcher. Saturation was achieved with 20 participants: 11 men and 9 women aged 26-85 years, with diverse educational and occupational backgrounds (Appendix 1). Time since diagnosis ranged from one week-13 years, treatment status from pre-treatment to post-treatment follow-up. Most index consultation were with a consultant; two and one, respectively, were with a specialist trainee or senior pharmacist. Five participants were interviewed at home; three had a partner present for all or part of their interview.

3.2 Overview and interpretive explanation

A striking feature of every patient’s account was the pervasive sense of uncertainty inherent in the illness, compounded by exposure to alarming information from non-clinical sources. This was the context for understanding the main finding: that most patients valued practitioners managing information for them, allowing patients to feel ‘in the picture’ without challenging their need for protection from overwhelming threat. A few patients recounted previous experience that made it hard to trust practitioners’ care, and these patients were not content with practitioners’ management of information.

3.3 The context of patients’ needs: the threat of an uncertain condition

Patients were aware of the seriousness of their condition. Most referred explicitly to the possibility of dying, and described the intense uncertainty of a changeable condition. They lacked a predictable trajectory of treatment and recovery because therapeutic options depended on evolving clinical features. They described their disease as “*a ticking time bomb*”(P1) so that, even though “*I thought*

I'd beat it...it changed and went more aggressive." A few explained that even their practitioners could not "*put their finger on*"(P10) what was wrong.

Patients were often alarmed by extraneous events that, although not explicitly related to their disease status, they interpreted threateningly, including unexpected telephone calls or letters inviting them to hospital, deaths of patients they befriended, or reports of public figures dying from haematological conditions. Non-clinical information sources were also apt to alarm. In particular, the Internet "*will frighten the life out of you*"(P9). Friends or family sometimes provided information, but only P12 described this positively because "*[sister] knows all about this, so she lets me have little dribs and drabs*". Others were alarmed by information from friends or family, as P15 illustrated: "*[Father] is trying to make me more nervous...He'll say 'Do you understand the situation' and 'How you can really be so calm?'*". Patients therefore generally avoided information from non-clinical sources, relying on what they were given by practitioners. For instance, P7 had received information from her son, who obtained it from colleagues in the drug company for which he worked, but she described feeling unable to make use of it, explaining: "*there's nothing we could do, we just accepted whatever [haematologist] said.*"

3.4 Patients needed practitioners to 'manage' information for them

Patients were, in general, confident that practitioners knew what information to give and realistic about lacking the expertise to understand all the information available. For example, P6 explained that "*they don't tell you everything...he's a doctor, he knows. If he thinks I should know he'll tell me...I just accept it*". This did not mean that practitioners generally denied information that patients wanted, as P15 explained: "*I haven't really asked them [about his subtype of Hodgkin's Lymphoma] but all the questions I have asked they have told me.*" From patients' perspective, practitioners' management of information had the three following elements.

3.4.1 Constraining information protected patients

In general, patients described feeling protected, and comforted, by practitioners constraining clinical information. P12 recounted being told of a “*T-cell that’s broken off*”. When asked if she wanted to know more, she replied “*No I’ll leave it and let [doctors] deal with it... just at the moment I don’t want to take in any more*”. Constraining information meant pacing, or “*drip-feeding*”(P20) it, but also avoiding detailed clinical information, particularly if it was threatening: “*No-one wants to have it sort of possibly spelled out that ‘No we can’t do anything more for you now’*”(P17). Several were explicitly asymmetric in their desire for information according to whether it was ‘good’ or ‘bad’, as P9 explained: “*You only want to know good news. I want to know how I’m going on if it’s good but if I’m not doing very well, better not knowing*”. Similarly, when prompted about asking questions of the clinical team, P7 replied: “*If the answer’s a bad one you don’t really want to know...bad news would just knock me down*”.

Patients actively collaborated in seeking protection from undesired information. They chose not to ask certain questions. For instance, after being told his cancer was “*higher grade*”, P16 “*never asked [what this signified]. I’m sure if I would have asked they would have told me.*” P20 illustrated how protecting himself from knowing the possible duration of treatment relied on being able to disregard information. When asked whether there was any information that he wanted but had not obtained, he replied “*No...although I’m sure I’ve been told but chose not to take it in, the worst case scenario of how long I’d be on the treatment...If I was told I was going to be on it for years initially it may have been a bit daunting...I probably was given the proper story but...chose not to recall it.*” Similarly, P15 “*can sort of filter things out what’s important to me, what I want to take in I’ll just take that in*”.

A few patients did refer to wanting specific clinical information they had not received but, elsewhere in their interviews, were ambivalent about it or indicated that they did not want it or could have obtained it had they wished (Figure 1). Three patients clearly wanted information that they had not been given (see ‘variant cases’ below). By contrast, several had received more information than they wanted, particularly during consent procedures when risk information associated with treatment felt “*overwhelming*” (P3).

3.4.2 Focusing on a tangible marker helped patients feel 'in the picture'

Patients valued practitioners providing visual markers of their condition. A few had seen scan images. For instance, P17 appreciated that “[haematologist] did actually show me...the PET scan and he was able to point out...hot spots...In all the time I've had this cancer...I've never actually felt ill with it...It's quite good to see in a way the visual image of 'Oh gosh, there are things there.’” Mostly, however, patients described blood markers. For instance, P20 recalled that his haematologist “did turn his computer around and he was showing me a chart, a graph of all the results”, even though “I can't remember which ones he showed me...Actually seeing a physical representation of the line actually dipping initially and then coming up...that worked for me.” Even when markers indicated deterioration, patients benefited. P9 recounted how his doctor “showed me the graph. Since that treatment it's starting to creep all the way back up and it's got to the level where it needs looked at”, explaining that it “puts me completely in the picture”. This kind of visual image helped patients in several ways (Figure 2).

3.4.3 Showing efforts to manage information demonstrated practitioners' caring

Most patients felt that practitioners had prepared for their consultation, deciding beforehand what information to give. Using one patient's account, Figure 3 illustrates the kinds of preparation that patients valued. Crucially, patients valued the preparation itself, regardless of specific information that ensued. That is, preparation indicated that practitioners cared. As P8 illustrated, his doctor made him feel “top of the agenda”, simply by telling him “they have a meeting about me every week”(P8).

The importance of preparation was salient for the few patients who sensed its absence. P19 spoke of being given a CT scan report which felt threatening because it indicated how advanced his condition was. He complained that “without giving me that [report] they should have explained where it [disease] was”. When her consultant was away, P17 recalled a doctor who “had obviously not looked at my notes and it was very, very unsatisfactory...I came away feeling... 'Oh no, that was not good', because she didn't know the full story...Perhaps something might not get back to the doctor when he returned”. P3 felt lack of care after a junior doctor delivered results: “It would've been good to see the

main person for such an important set of results, felt important to us anyway, perhaps it wasn't so important for them".

3.5 Patients managed information for others

Just as they described practitioners managing information for them, patients in turn managed information for family to avoid 'worrying' them, creating 'take-home' messages such as "*The treatment...is working and things are diminishing', that sort of thing and they...always say... 'That's great to hear'.*"(P17) or even providing incorrect information: "*I just told them like it was in two areas and actually it was in three or four...I just didn't want to worry them*"(P15). A few, such as P6, managed information for friends: "*I'll just say 'Oh its clearing up', but thing is, you're going to say that anyhow even if it wasn't, you're going to put a 'Oh they reckon it's doing well' on...When you've got cancer like, the word frightens people*"(P6).

3.6 Variant cases: patients with unmet information needs

Most patients' trust in practitioners to tell them what they needed to know was resilient to isolated challenges, such as finding a doctor unprepared. However, three patients described persistent, unmet information needs (Appendix 2). One had a strong sense of her own specialist knowledge and was not content with practitioners managing information for her. Two others recounted apparent failures and delays in diagnosis and management that had challenged their ability to trust practitioners.

4 DISCUSSION

4.1 Main findings

To our knowledge, this is the first study to identify the importance haematological cancer patients placed on practitioners 'managing information for', rather than 'giving information to', them. Despite intense uncertainty associated with their illness, patients did not, in general, want extensive clinical or prognostic information. Instead, trusting caring practitioners to select and manage information allowed patients to feel informed. Most trusted their practitioners and felt informed. The few who

wanted more information than they received did not fully trust practitioners to manage information for them.

4.2 Findings in relation to literature

The findings are consistent with quantitative evidence that patients with haematological cancers generally feel informed, despite variable knowledge of their condition(15,16,17). They are also consistent with previous qualitative findings that point to the clinical relationship as the key to how such patients can feel informed in a context in which information can be complex and threatening(17). However, our findings go beyond confirming the clinical relationship as the necessary context for feeling informed, to indicate the active role that both parties take in managing information.

Given the intense threat and sense of vulnerability associated with the uncertainty inherent in their condition, patients were apt to interpret extraneous events or information from sources other than practitioners as alarming. To protect themselves, they sought information preferentially from practitioners, selecting what they wanted to hear either by choosing what to ask or by selective hearing and remembering of what practitioners told them. Patients were not, in these ways, 'denying' their condition. Aware of its seriousness, they chose to avoid information that they knew or feared would be threatening, a psychological process that Salander termed 'disavowal'(26). Patients also selected information for family and friends. While their stated motivation was to protect others(27), they thereby also protected their own disavowal from being challenged by others' enquiries or sympathy.

Patients also needed practitioners to manage information for them. Previous reports have shown that patients want practitioners to limit information, including in haematological cancers(10). However, our findings show the importance of practitioners *managing* information, not just limiting it. This meant, for example, showing graphs and other tangible markers that helped patients feel 'in the picture'. Crucially, patients wanted practitioners to give information asymmetrically; that is, to give information freely where it was 'good', but sparingly where it was 'bad', as reported previously in breast cancer(11) and in parents of children with leukaemia(28). Our findings build on Perakyla's

account of practitioners' role in 'hope work' in the context of life-threatening illness(29). Patients gave them this role, and could then collaborate with practitioners in constructing a picture of the future which sustained their hope(30).

Research and policy literature on patients' information needs in cancer typically refers to information as a 'quantity'; i.e. it focuses on 'how much' information patients want about different topics. Our participants' accounts indicated the limitations of this unidimensional view which disregards the different ways in which information can be conveyed. Patients valued practitioners' use of visual representations to simplify information, many appreciating being shown graphs on practitioners' computers that made sense of treatment decisions, even if they did not remember the markers plotted. Being given this information helped patients accept what they were told about treatment(31).

Appreciation of practitioners managing information went beyond the informational value of what patients were told or shown. Patients felt comforted by knowing that practitioners had thought about what information to provide. That is, patients inferred practitioners' caring from how considerately they managed information, just as they might infer caring from how sensitively practitioners conducted a physical procedure.

The responsibility that patients give practitioners for constraining and managing information resembles that in patients with solid tumours(11, 30, 32, 33), but is inconsistent with influential views of patients as 'partners' in care, to be 'empowered' by information. Indeed, only one 'variant' patient took this stance, and she was unusual in the sense of medical authority she felt. The responsibility is, though, consistent with suggestions that clinical relationships in cancer resemble attachment relationships(34, 35, 36, 37). That is, patients attribute to practitioners the expertise and authority to look after them and to know what they need – including what information they need. This perspective helps explain why patients relied primarily on practitioners for information, disregarding the Internet or family members; they felt that only practitioners could take responsibility for managing information for them.

Our findings are also inconsistent with the separation in clinical communication research between affective and cognitive components of clinical communication(38). Patients' experience of being informed was interconnected with their sense of relationship. Patients felt informed, not necessarily because of information they received, but because they knew that practitioners whom they trusted were managing all their care, including information. Conversely, feeling that practitioners were managing information was itself evidence that they cared.

4.3 Study limitations

The inductive design allowed us to explore what mattered to patients and thereby to challenge influential assumptions around information needs. As a qualitative study, however, the results cannot automatically be generalized; patients were recruited from one clinic and findings might differ in others. The sample was clinically diverse because we sought findings relevant across the range of disease subtypes and treatment trajectories in haematological cancers; we might not have identified processes relevant to specific patient groups. Nevertheless, the theoretical validity arising from convergence with previous studies in haematological cancers and other tumour groups suggests that our findings potentially have broad transferability.

4.4 Clinical implications

Although clinical communication policy typically assumes that patients need information to inform decisions(7), we saw this in only one, 'variant', patient with an unusual sense of her own medical authority. Instead, the main implications of our findings arise from the interconnectedness of information and clinical relationship.

Research typically concludes that 'unmet information needs' in haematological cancer patients should be addressed by giving more information(17). However, our participants had mostly learned to avoid sources that provided information freely (i.e. those outside the clinical relationship), finding that more information was not the key to feeling informed; indeed, unmanaged information could make them feel less informed. Kalanithi likened this paradox to trying to quench thirst with salt water(39).

Instead, as Kalanithi also illustrated, patients relied on practitioners to judge what information they needed and manage information for them, not just respond to their requests(39). Most patients in our sample readily trusted practitioners and therefore felt informed. Where unmet information needs arise, they might indicate problems to be addressed in the clinical relationship(17). For instance, two patients felt overlooked during their care, lacked full trust in the care team, and expressed unmet needs for more, or more consistent, information.

While practitioners need to respond to specific questions that such patients have, they also need to address the difficulties in trust that form the background to those questions. Although distribution of care across a multidisciplinary team might militate against the kind of attachment relationship that can help patients trust practitioners to manage information, a clinical team and its efficient operation might have properties of an attachment figure so that patients can feel comforted by being admitted into a 'caring plan'(40). Nevertheless, the uncertainty and unpredictability in haematology makes such a 'plan' elusive for some patients, particularly those who have difficulties trusting practitioners. Therefore one way to facilitate patients' trust might be to ensure that they know that a single practitioner, whom they see periodically or at turning points in treatment, oversees their care, i.e. that they have a 'secure base'. This person could prepare the patient explicitly for potential difficulties around trusting practitioners when the course of treatment and illness is so unpredictable. Practitioners could also explain to patients their experience of working with uncertainty and that, where unpredicted events arise, there is a plan to manage these.

4.5 Conclusion

The overriding message is that patients did not want to take responsibility for judging what information they need. In the context of a trusting relationship, patients relied on practitioners for this role, as for other aspects of care. Practitioners will therefore inevitably sometimes give more or less information than patients want, and will need to be alert to needs they had not identified. However, while practitioners need to provide patients with the information they seek, they also need to

recognize that seeking more information can indicate patients' difficulty in forming a trusting clinical relationship.

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Figure 1. Five patients, including those illustrated here, said that they wanted specific information, but elsewhere in the interview indicated ambivalence.

| Talk suggesting information needs | Indications of ambivalence |
|--|---|
| <p>P19 had received a copy of a clinical report – “<i>a piece of paper which said about the sites [of his lymphoma]</i>” – and complained that “<i>I've never been told what those sites are and if it's cancer or if it's nodules. It says 'nodules' but are they cancer nodules? Are they? Just, I don't know</i>”</p> | <p>Returning to this later in the interview he explained that: “<i>I know if I asked [nurse] she'd tell me, so I can only conclude really that I don't really want to know</i>”.</p> |
| <p>P17 had felt helped by seeing a PET scan that allowed her to visualize her asymptomatic Hodgkin's Lymphoma (see below), and “<i>was a little bit disappointed [not to be shown a post-treatment scan]...I was hoping to see a screen with no hot spots. So I'm taking his [doctor's] word that it's [monoclonal antibody treatment] working but, you know.</i>”</p> | <p>She had not asked to see the PET scan. Nevertheless, given her experience of previous episodes of (unrelated) cancer she explained elsewhere in the interview that “<i>because I'm older, more experienced and all the things that have happened over the years I would certainly ask, question things now and ask things if I wasn't sure about something or wanted a bit more detail about something</i>”.</p> |

Figure 2. Referring to being shown a chart on her doctor’s computer that tracked a specific protein indicator, P7 illustrated the range of reasons why patients valued such visual ‘markers’.

| Function of the information | Illustrative text |
|--|---|
| Enhanced trust in the doctor. | <i>“[Doctor] is absolutely wonderful, big charts [on doctor’s computer screen] every time and he explains everything. Very reassuring, he’s very, very good.”</i> |
| Explained clinical decisions. | <i>“I went for a few months and then I think my blood went up and up and up. Showing me this chart, and he said ‘I think we’re going to have to start the chemo’, and he took me straight away to the chemo.”</i> |
| Anchored understanding of the illness. | <i>“The protein level, this is what started the whole thing in the first place. It got so high that blood was going so slow around my body...Protein levels have gone up to a level where they need to be treated again.”</i> |
| Managed emotion in consultation. | <i>“Something to look at [in consultation]...obviously you’re a bit emotional and if you can look at something...as opposed to looking at somebody, if it’s bad news...that kind of helps.”</i> |

Figure 3. P1 illustrated the range of ways in which patients recounted their practitioners preparing for consultation.

| Form of preparation | Illustrative text |
|--|--|
| Selected information. | <i>“I suppose you have to make judgement calls don’t you, on how you tell people, what you tell people, in the time that you’ve got”.</i> |
| Took account of patient’s ability to manage or understand information. | <i>“They’d discussed and wondered how much to tell me but because I’d asked, I was knowledgeable and asked questions, I knew that they’d given me the full information”.</i> |
| Arranged take-home material. | <i>“He gave me loads of paper, booklets and different websites so I’ve got all the information to hand”.</i> |
| Met with other professionals to discuss patient’s needs and adjust care accordingly. | <i>“[Counsellor] had already been in and said ‘[patient] is waiting and she’s nervous’”.</i> |
| Knew the results to be delivered in advance. | <i>“As soon as I got in he just blurted out ‘It’s good news’, so yeah, which was relaxed, just relaxed me straight away.”</i> |

Appendix 1. Sample characteristics

| Participant number | Gender | Age-band (years) | Highest level of education | Most recent job type | Present work status | Diagnosis | Time since diagnosis | Clinical situation | Results given at index consultation ¹ | Significance of results | Time post-index consultation when interviewed (days) | Place of interview |
|--------------------|--------|------------------|----------------------------|-------------------------|---------------------|-------------------------------|----------------------|--------------------------|--|--|--|--------------------|
| 1 | Female | 30-35 | Higher education | Professional/Management | Sickness absence | Non-Hodgkin's lymphoma | 6months | Mid-course of treatment | CT scan ³ | Treatment effective: continue | 7 | Hospital |
| 2 | Female | 55-60 | Higher education | Care | Sickness absence | Non-Hodgkin's lymphoma | 2weeks | Newly diagnosed | Blood tests | More detailed diagnosis and treatment implications | 2 | Home |
| 3 | Male | 65-70 | Higher education | Professional/Management | Retired | Non-Hodgkin's lymphoma | 8months | Post-treatment | CT scan ² | Treatment effective | 2 | Home |
| 4 | Male | 50-55 | School | Manual | Working | Chronic lymphocytic leukaemia | 10years | Recently began treatment | Blood tests | Treatment effective: continue | 14 | Home |
| 5 | Female | 80-85 | School | Manual | Retired | Chronic lymphocytic leukaemia | 13years | Mid-course of treatment | Blood tests | Treatment effective: continue | 14 | Home |
| 6 | Male | 70-75 | School | Manual | Retired | Hodgkin's lymphoma | 5months | Mid-course of treatment | PET scan | Treatment effective: continue | 14 | Hospital |
| 7 | Female | 65-70 | Higher education | Professional/Management | Retired | Chronic lymphocytic leukaemia | 2-3years | Mid-course of treatment | Blood tests | Treatment effective: continue | 28 | Hospital |
| 8 | Male | 50-55 | School | Manual | Sickness absence | Non-Hodgkin's lymphoma | 6years | Mid-course of treatment | CT scan and blood tests | Treatment effective: continue | 28 | Hospital |
| 9 | Male | 65-70 | School | Manual | Retired | Non-Hodgkin's lymphoma | 5years | Watchful waiting | Blood tests | Indicate need to start treatment | 14 | Hospital |
| 10 | Male | 75-80 | Higher Education | Professional/Management | Retired | Chronic lymphocytic leukaemia | 2-3years | Watchful waiting | Blood tests | Indicate need to start treatment | 28 | Hospital |

| | | | | | | | | | | | | |
|----|--------|-------|------------------|-------------------------|------------------|-------------------------------|----------|---|--|--|----|----------|
| 11 | Female | 30-35 | Higher education | Professional/Management | Sickness absence | Hodgkin's lymphoma | 4months | Mid-course of treatment | PET scan | Indicate need for increased treatment dose. | 14 | Hospital |
| 12 | Female | 65-70 | School | Office/Clerical | Retired | Non-Hodgkin's lymphoma | 1week | Newly diagnosed and under investigation | CT and MRI scan | Confirm diagnosis and disease location | 7 | Hospital |
| 13 | Female | 50-55 | Higher education | Care | Working | Non-Hodgkin's lymphoma | 7years | Watchful waiting | Stomach biopsy, ultrasound, blood tests ² | No intervention required | 14 | Hospital |
| 14 | Female | 60-65 | School | Office/clerical | Retired | Chronic lymphocytic leukaemia | 2years | Awaiting start of treatment | CT scan and blood tests | Start treatment imminently | 7 | Hospital |
| 15 | Male | 25-30 | Higher education | Professional/Management | Sickness absence | Hodgkin's lymphoma | 2months | Mid-course of treatment | Blood tests | Treatment effective: continue | 14 | Hospital |
| 16 | Male | 25-30 | School | Manual | Sickness absence | Non-Hodgkin's lymphoma | 2weeks | Mid-course of treatment | PET scan and blood tests | More detailed diagnostic information with treatment implications | 7 | Hospital |
| 17 | Female | 60-65 | Higher education | Office/clerical | Retired | Hodgkin's lymphoma | 14months | Mid-course of treatment | PET scan and blood tests | Treatment effective: continue | 21 | Home |
| 18 | Male | 60-65 | School | Manual | Unemployed | Chronic lymphocytic leukaemia | 3years | Watchful waiting | Blood tests | No treatment needed | 5 | Hospital |
| 19 | Male | 60-65 | School | Office/clerical | Retired | Non-Hodgkin's lymphoma | 3months | Recently started treatment | Blood tests | Treatment effective: continue | 5 | Hospital |
| 20 | Male | 40-45 | Higher education | Professional/Management | Working | T-cell leukaemia | 6months | Mid-course of treatment | CT scan and blood tests | Treatment effective: continue | 21 | Hospital |

¹In the index consultation patients' results were given by ²a specialist trainee in haematology or ³senior pharmacist where shown above; all others were given by a consultant haematologist.

Appendix 2. Variant cases: three patients indicated that they wanted information that they had been unable to obtain.

P13's need arose from her own sense of medical knowledge and authority.

Diagnosed with MALT Lymphoma 7 years previously, she had not yet needed treatment. Having *"always had a fascination with human biology"* and having done *"all my nursing qualifications"* she felt that *"over the years that I've been coming as a patient I've always known what they [doctors] were talking about"*. She thought her knowledge sometimes surpassed doctors'. For instance she described telling a surgeon immediately before previous gynaecological surgery *"how to cut and where to cut"*. She routinely used clinical information to monitor her treatment and watch for *"red lights"*. She wanted to know why practitioners continued to ask for blood samples, given her understanding that blood samples at diagnosis had not detected her lymphoma. She had asked this *"numerous times and never been given an answer...What are they looking for that didn't show up [then]? That's what is bamboozling me...And no-one gives me an answer."*

Two others recounted a history of perceived failures in care that reduced their trust in practitioners.

For P3, lack of continuity had left him feeling overlooked and with inconsistent information; he wanted a single practitioner to take responsibility.

He described a year of undiagnosed poor health before his diagnosis, managed by his general practitioner (GP) culminating in emergency hospital admission during which he was diagnosed with lymphoma. He had lost trust in the GP (*"You never see the same doctor twice hardly anyway"*), a pattern repeated in hospital care: *"One of the worst things about the [diagnostic] process, you get passed on from one person to another to another and nobody knows you, you're just a file"*. In the haematology clinic, he linked continuing discontinuity to not feeling cared for; for post-treatment results he saw a doctor new to him: *"it was the first time she [doctor] had picked up my file...If it'd been bad, then it'd be somebody who I'd never seen before telling me...I didn't like that"*. Discontinuity also led to *different kinds of stories...If [the same] person had said something back here you could say 'Why has that changed?' But if the one who's saying it's a different person then they probably don't know"*. For P3, the solution was that *"at certain points you see the same person...at some point somebody comes in and says... 'I've had a look at it and everything's OK but I'm passing you on to so and so who'll deal with you for the next two but I'll see you again on whenever'"*.

P11 similarly felt a lack of caring in the pre-diagnosis period. Now, she wants to see the PET scan results that would validate her practitioners' report that her treatment was working.

She felt *"fobbed-off"* during her journey to diagnosis of Hodgkin's lymphoma, initially by a GP who attributed her symptoms benignly, then by hospital staff who could not perform a planned biopsy when she attended for it and then did not have results available for her outpatient appointment. Once she started haematology treatment she received printed information sheets but felt overlooked as an individual. Now she wanted to see images from her recent PET scan *"for my own peace of mind"* to confirm what her doctor had told her: *"I know its [tumour] shrunk but...no-one has gone through that really although I have asked."* She complained that: *"I've asked to see [scan images]...they kept saying they would bring them but...But I have still not seen them."*