

# **A qualitative study of the barriers and enablers to administration of supportive therapy closer to home for breast cancer patients**

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## Abstract

### **Background**

The NHS Five Year Forward View and NHS Cancer Strategy have identified as a priority the increased use of primary care to deliver services traditionally seen in secondary care. Denosumab is a subcutaneous injection that is administered in secondary care once monthly to people at increased risk of skeletal events following metastatic solid tumour cancers. The project was conceived following discussions within one London local health economy about exploring alternative options for care delivery. Changing the delivery arrangements for this medicine could impact on GPs (who deliver the majority of medical treatment in primary care) and patients (who receive the treatment).

### **Purpose**

This research aimed to understand the barriers and enablers to administration of denosumab in the community by understanding and exploring views of GPs in north London when considering prescribing specialist medicines, and by evaluating the experiences and wishes of patients receiving denosumab therapy at the University College London Hospital MacMillan Cancer Centre.

### **Methods**

A qualitative study using semi-structured interviews with six GPs and four patients was conducted. Interviews were audio recorded and transcribed verbatim. GP interviews were analysed against a framework designed to understand professional barriers to implementing evidence based medicine. Patient interviews were analysed against a framework based on touchpoints in cancer care, with further inductive identification of themes.

### **Results**

Five domains emerged as major influences on barriers and enablers to GPs prescribing specialist medicines. These domains were (1) Knowledge, (2) Social & professional roles, (3) Beliefs about capabilities, (4) Beliefs about consequences, and (5) Environmental context & resources.

Patient interviews identified waiting times as a dominant theme. The majority of patients believed that denosumab could be administered by anyone (even by self administration), but there was not universal support for having this treatment removed from the cancer centre.

## **Conclusions**

This study provided valuable insights into GP and patient perspectives on redesigning delivery of services from secondary to primary care. These findings highlight focus areas for future interventions and initiatives to enable GPs to take on more specialist service delivery.

Future design of denosumab administration services should acknowledge that most patients were happy to receive the medicines in any setting though multiple options may need to be provided to patients as they may prefer the security of the Cancer Centre.

## Introduction

Improvements in health care efficiency feature highly on the government's agenda for the National Health Service in the UK. As part of the NHS Five Year Forward View, health care managers were encouraged to identify opportunities for delivering care in the community rather than in hospital, such as through Multi-Speciality Community Providers or Primary and Acute Care Systems. [1] Additionally, the NHS Cancer Strategy includes scoping the feasibility of delivering aspects of cancer care (including chemotherapy) in community settings. [2] However, progress on both of these policies is variable.

GPs remain the most well-known and easily identifiable providers of care in the community [1], and are often required to take on prescribing of medicines that have been initiated in secondary care. When this is carried out in a collaborative manner, it is commonly known as shared care, which has a long history. [3] [4] [5] [6] General Medical Council advice on Prescribing and Managing Medicines and Devices (2013) states that GPs have responsibility to work within their limits, whilst keeping knowledge and skills up to date. [7] GPs are responsible for any prescription they sign, even if it is being prescribed at the recommendation of a specialist colleague. [7] As this GMC guidance is open to individual interpretation by practitioners, there is scope for variability in what might be acceptable; formulary committees must keep this in mind when making local prescribing recommendations.

Denosumab subcutaneous injection was licenced in the UK for prevention of skeletal related events in adults with bone metastases from solid tumours in 2011 [8]; in October 2012 it received a positive technology appraisal from NICE. [9] These approvals mean denosumab could be considered an innovative therapeutic agent. For a range of innovation types (e.g. farming practices, use of fast-moving consumer goods), adoption of the innovation follows an S-shaped curve, with adopters separated into distinct groups based on the speed with which they take on the new technology: innovators, early adopters, early majority, late majority, laggards. [10] The application and transferability of this pattern to prescribing practices has been debated. [11] [12] Differences in adoption of a new drug by prescribers may be influenced by internal (such as past experience, professional confidence) as well as external (e.g. information received from the health authority or professional peers) characteristics. [12] [13] This results in variation of the extent to which individuals are willing to innovate. In one study it was identified that 42% of primary care prescriptions for recently

marketed drugs were written by 10% of general practitioners. [14] Subsequent to these studies being published, the NHS has undergone a significant reform, [15] therefore it is important to further explore the views of GPs working now to identify what barriers and enablers to prescribing specialist medicines they are experiencing.

Experience of the system is one of the three aspects of a well-designed service, together with functionality and engineering (safety), however this experience is hard to access directly as it cannot be done through observation. [16] [17] Participation of patients in health care planning and service evaluation has been used in the NHS for well over a decade, with variable amounts of engagement and success. [18] [19] [20] Indeed, knowing the perspective of the patient was identified by The Kings Fund as an essential step if health care providers hope to successfully improve patient experience. [21]

The purpose of this study was to identify the barriers and enablers to the administration of supportive therapy to patients with cancer, closer to home. The aim was to understand the perspective of patients and GPs, who were unlikely to have been involved in the initial decision making about the service redesign, but would be affected by the service redesign implementation. The objectives were to:

- Understand and explore views of GPs in north London when considering prescribing specialist medicines
- Determine the experiences and wishes of patients receiving denosumab therapy at the UCLH MacMillan Cancer Centre.

## Methods

This qualitative study used semi-structured interviews conducted by a pharmacist (JM) experienced in medicines policy decision making at the primary-secondary care interface to deeply explore the experiences and views of interviewees about the subject matter. Interviews were conducted between June and September 2017. They were audio-recorded and transcribed verbatim. One researcher (JM) compared all transcriptions to the audio recordings to ensure accuracy of the transcript. NVivo version 11 was used to manage the data.

### GP Interviews

For the semi-structured interviews with the GPs, an interview schedule was developed collaboratively by three researchers (JM, YJ and LJ) (see Appendix 4: GP Individual Interview Protocol). This schedule included “critical incident” questions, which have been used effectively in similar research to force the participant to recall a specific incident about which they are able to describe their thought processes. [22] [23] The researchers acknowledged that GPs might not be familiar with the medicine denosumab, so the questions did not focus on this specifically. Instead, the focus was on the broader issue of being asked by a specialist to prescribe a new medicine.

The GP interviews were analysed using a framework developed Michie et al to understand professional barriers to implementing evidence based medicine. [24] This framework was chosen as it consisted of twelve wide-ranging domains to explain behaviour change with regards to professional practice (see Figure 1 and Appendix 6: Michie Domains [full details]).

1. Knowledge
2. Skills
3. Social & professional role/identity
4. Beliefs about capabilities (self-efficacy)
5. Beliefs about consequences
6. Motivation & goals (intention)
7. Memory, attention, decision processes
8. Environmental context and resources
9. Social influences (norms)
10. Emotion
11. Behavioural regulation
12. Nature of the behaviours

*Figure 1 Michie domains to investigate implementation of evidence-based practice*

## Patient Interviews

Patient interviews followed a methodology called “discovery interviews”, which is designed to elucidate which aspects of the care process are important. [24] [25] An interview schedule was developed collaboratively by three researchers (JM, YJ and LJ), which again included “critical incident” questions and “diary questions”. The two “diary questions” were placed at the start of the interviews to provide participants with the opportunity to be introduced to the topic under evaluation, and to highlight what is important to them. [26] See Appendix 5: Patient Interviews Protocol.

These semi-structured discovery interviews explored patient experiences of the denosumab administration service. This method was chosen as in-depth, narrative interviews are recognised as the first stage of Experience-Based Co-Design (EBCD), a methodology gaining favour as it is able to harness the inner experiences patients to help design responsive, safe and effective services. [16] [27] [28] This relies on the experience of a patient and is distinct from the concept of patient satisfaction in that, through use of exploratory tools, it is able to account for confounding aspects such as patient expectations and specific patient characteristics that affect how they respond to stimuli. [21] It also refocuses the question on to what is important for the patient, rather than what is a priority for the service manager. [21] The researchers also decided that surveys would be an inadequate tool to evaluate experiences of patients as they do not offer any scope for exploring an individual’s experience beyond what has already been anticipated when the survey is designed. [16]

A framework for the initial analysis of the patient interviews was generated based on previous research looking at touchpoints in cancer care. [24] [25] Following a thematic analysis of in-depth interviews and surveys, Tsianakas *et al* [24] identified six touchpoints in the cancer care process that are relevant for this study. These touchpoints, see Figure 2 below, were part of a subgroup that the authors called “moving through the system”. [24]

1. Long waiting times in clinic
2. Administrative issues (making and co-ordinating appointments; receiving letters on time)
3. Lack of continuity of care
4. Positive impact of friendly front line-staff
5. Satisfied with speed of moving through the process
6. Need for better communication

*Figure 2: "Moving through the system" framework*

Following close reading of all the transcripts, this framework was supplemented by inductive development of further touchpoint themes relevant to patients using the service at UCLH

Macmillan Cancer Centre. This was based on emotional touchpoint work described by Dewar *et al.* [29] An iterative approach was taken to ensure new domains were applied appropriately to all transcripts.

## Participants

Recruitment of General Practitioner participants followed a combination of purposeful and convenience sampling. [22] [30] Any GP was eligible for inclusion in the study if they provided at least one session of care in north London. Exclusion criteria for GPs was limited to unwillingness to give informed consent. A convenience sample of GPs meeting the inclusion criteria who were known to the researcher was identified to participate in this research. Two additional participants were identified through a snowballing approach, which relied on colleagues aware of the project suggesting GPs with an interest in provision of cancer supportive care. Heads of Medicines Management in North Central London were approached to disseminate the information about the research among local GPs, with one Clinical Commissioning Group (CCG) sharing details of the research through their bulletin email.

The sampling methodology employed to recruit GPs was considered to be appropriate as it balanced the priorities of recruiting a knowledgeable cohort of participants willing to spend up to 60 minutes of time and availability of resources to conduct the study. Purposeful sampling ensured that there were a mix of genders, together with both partner and salaried GPs. In total, a sample of six GPs from practices in London participated in the interviews. One GP initially responded to the invitation but didn't consent to participate. No GPs dropped out of the study.

Patients were identified and recruited to the study from using clinic lists at University College London Hospital NHS Trust Macmillan Cancer Centre for administration of denosumab. The sampling technique was chosen as the study aimed to evaluate the service provided specifically by this treatment centre. This produced a "critical case sample", all of whom had specific experiences of having received denosumab treatment in the same setting. Patients on the list were contacted either on the day they were scheduled to receive denosumab treatment or a couple of days before their scheduled appointment. All patients on the list were contact via telephone, with those responding to the telephone call being approached personally or via email to receive information about the research project. Direct contact was made with ten patients to invite them to participate in the evaluation; two refused to participate, two did not respond to the request, one was not able to participate because she didn't speak English and a sixth was ineligible for inclusion because she was not

receiving denosumab therapy.

Neither patient nor GP interviews were incentivised in order to ensure rational use of the research budget.

### **Ethics**

According to NHS Health Research Authority decision toolkit, this project did not require research ethics approval: the patient interviews were “service evaluation” and therefore exempt. [31] [32] The GP interviews were classified as research, but this staff group are exempt from NHS ethics approval because they are not employed staff. [33]

To maintain the principles of research ethics, all participants were provided with written information about the research before being asked to consent to participate. Patients were provided with a detailed information leaflet about the evaluation (see Appendix 1: Patient Information Leaflet), which included details of people they could contact for support should the interviews raise any questions for them. The design of this leaflet was based on an example produced by NHS Wales. [34] Written informed consent was obtained from all participants before starting the interviews (see Appendix 2: Patient Informed Consent and Appendix 3: GP Informed Consent). Audio recordings of the interviews were deleted once they had been transcribed and verified. Transcripts were stored anonymously.

## Results

### GP Interviews

Six of the twelve GPs contacted directly by the researcher agreed to participate in this study. Interviews were conducted with six GPs (4 female, 2 male) either at their practices (n=5) or in the offices of their CCG. Four GPs were based in north central London, one GP in north west London and one GP in north east London. All interviews were conducted in a private room to maintain confidentiality. Each interview was scheduled to last 60 minutes, though the actual length ranged from 30 to 45 minutes.

Based on twelve domains of the Michie *et al* (2005) framework (see Figure 3), five domains emerged as dominant themes describing the barriers and enablers that GPs experience when prescribing specialist medicines: (1) Knowledge, (2) Social & professional roles, (3) Beliefs about capabilities, (4) Beliefs about consequences, and (5) Environmental context & resources.

### Framework Analysis

Framework domain	Interview theme
Knowledge	<ul style="list-style-type: none"> <li>• Where information can be found (clear documentation)</li> <li>• What monitor is needed</li> <li>• Ordering and storage (how to)</li> </ul>
Skills	<ul style="list-style-type: none"> <li>• Straightforward injection</li> <li>• Appropriate utilisation of health care team skills</li> </ul>
Social & professional role/identity	<ul style="list-style-type: none"> <li>• “Cradle to grave and continuity”</li> <li>• Adherence to code of conduct</li> <li>• Is most appropriate HCP available</li> <li>• Credibility of source recommending</li> <li>• Clear communication</li> </ul>
Beliefs about capabilities (self-efficacy)	<ul style="list-style-type: none"> <li>• Little is outside the ability of the GP</li> <li>• Practice skill-mix supports personal ability</li> </ul>
Beliefs about consequences	<ul style="list-style-type: none"> <li>• Risk of interactions</li> <li>• Serious adverse events may occur</li> <li>• GP does not have facilities to deal with very serious adverse events</li> <li>• Lack of knowledge about the long-term side effects</li> <li>• “Waiting” is consequence of visiting hospital</li> </ul>
Motivation & goals (intention)	<ul style="list-style-type: none"> <li>• Appropriate funding of services</li> <li>• Looking after patients</li> <li>• Adhering to delegated budgets</li> <li>• Feeling like valued partner (not dumped on)</li> </ul>
Memory, attention, decision processes	<ul style="list-style-type: none"> <li>• Remembering monitoring required</li> <li>• Clear information can facilitate decision process</li> <li>• IT can support memory</li> </ul>
Environmental context and	<ul style="list-style-type: none"> <li>• Clinical needs to patients registered at practice</li> </ul>

Framework domain	Interview theme
resources	<ul style="list-style-type: none"> <li>• Composition of team – how are you supported to carry out role</li> <li>• Facilities fit for new purpose</li> <li>• How time/rooms scheduled within a practice</li> <li>• Appropriate systems: blood tests, patient recall</li> <li>• Language barriers</li> <li>• Funding</li> </ul>
Social influences (norms)	<ul style="list-style-type: none"> <li>• Wider practice team influences decision making</li> <li>• Medicines Management pharmacists can influence based on agreed policy</li> <li>• NHS policy will have influence on role played by GP</li> <li>• Monitoring and regulatory agencies impact on how GPs perform their role</li> </ul>
Emotion	<ul style="list-style-type: none"> <li>• “Stupidity” when systems have no “leeway” for common sense</li> <li>• Disheartened when feel GP dumping occurring</li> <li>• Awkward if unsure if <i>should</i> know something</li> <li>• Confusion or annoyed when responsibilities poorly communicated</li> <li>• Anxious whether the patient will remember to book a follow-up appointment</li> <li>• Aiming to feel “comfortable”</li> </ul>
Behavioural regulation	<ul style="list-style-type: none"> <li>• Well-developed shared care can support a GP to take on prescribing</li> <li>• Having a clear link back to the specialist influences prescribing decisions</li> </ul>
Nature of the behaviours	<ul style="list-style-type: none"> <li>• Performing tasks that are repeated allows them to become habits and be performed well</li> </ul>

Figure 3: "Implementing evidence-based practice" results from GP interviews

### Knowledge

This domain assesses the extent to which a professional knows the technical aspects of a medicine, for example monitoring requirements, or how this medicine fits into guidelines. In the terms of this research, the domain was used to assess the extent to which GPs questioned their knowledge, using this as a proxy for the process they will follow if asked to prescribe a specialist medicine.

All respondents acknowledged limits to their knowledge, though how they deal with this when presented with a new prescribing situation differed between the respondents. Three respondents described how they search for more information, which included using the BNF, attempting to make contact with an appropriate hospital specialist, and contacting the Medicines Management Team. The Medicines Management Team was described as a resource that would be able to provide clinical information about the drug in addition to

policy advice (e.g. whether the drug appeared on the list of medicines that should only be prescribed in secondary care). In addition to speaking to the medicines management team, one GP also reported regularly contacting the pharmacist in the attached community pharmacy when he needs additional information about a medicine.

The types of information that commonly came up as a knowledge requirement were side effects, interactions and the monitoring schedule. GPs requested that instructions on monitoring a medicine need to be both clear and achievable. An example given was from anticoagulation clinics asking GPs to monitor creatinine clearance despite the blood results available on their systems having only calculated eGFR (a slightly different measure of kidney function). Although the computer system is able to support GP knowledge by providing information on all interactions, one GP respondent reported that this can be difficult to use as it alerts you to all interactions rather than prioritising the key ones to be aware of.

There is an element of feeling obliged to double check the process by which the specialist decided to prescribe a particular medicine, which requires GPs to ensure they are up-to-date with guidelines for all of the different conditions they are likely to encounter. For example, NICE's consideration of a medicine was quoted by one GP as being part of his decision process when considering taking on prescribing [GP3]. A second GP indicated that he also finds himself challenging medicine selection decisions if he doesn't feel the choice is consistent with recognised guidelines or pathways [GP4].

The majority of interviewees discussed information needs about dose, monitoring and interactions of medicines. One interviewee [GP2] raised that she would need to think about shelf-life and storage temperature requirements if she would be expected to administer a medicine.

Two GPs reported wanting to be aware of whether the medicine was licensed for the indication prescribed, with one reporting that he wrote to a consultant saying he couldn't take on prescribing because it wasn't licensed. This indicates a serious consideration of GMC guidance about where responsibility for unlicensed medicines lies.

This view was echoed by two other GPs, who said that the existence of a shared care protocol would improve the likelihood of taking on prescribing from a specialist. Provision of a "quite a lot of detailed literature about it" [GP3] would make it easier to prescribe by improving the prescriber's knowledge of the medicine.

When asked to think about specialist medicines that she remembered being asked by a consultant to prescribe, one GP reeled off a varied list of conditions that ranged from paediatrics, urology, neurology, psychiatry and rheumatology. This emphasised the variable nature of general practice; an important factor when considering the ease with which a GP may have capacity to remember enough about an individual medicine to prescribe and monitor it safely.

### **Skills**

Having the skills to perform a task (as opposed to having the knowledge) was identified as a theme relevant to prescribing multiple medicines, including denosumab. Denosumab administration is a subcutaneous injection, which was described by one GP as a “fairly straightforward” injection [GP1]. There was no concern that GPs wouldn’t be skilled enough to administer this injection. Additionally, the injection would most likely be administered by a nurse, who is also very likely to be experienced in administering subcutaneous injections. One respondent [GP6] was very clear that the actual route of administration of a drug was less important than other characteristics (e.g. side effects, monitoring requirements) because the administration procedure is usually easy to learn.

One interviewee recalled a time when she was asked to administer an intramuscular contraceptive injection, which was a procedure she had only carried out a handful of times before, which caused uncertainty for her. She agreed to perform the injection despite feeling “on edge” about getting it right [GP2].

### **Social & professional role/identity**

This domain accesses concepts of identity and the expectations of society on a professional. The GPs interviewed described the role they play within community. Their role as gatekeepers to the wider health system meant they were often relied on to liaise between patients and the specialist. It was felt by one GP that this societal role results in them taking on prescribing for some medicines purely to ensure patients do not have breaks in treatment, whilst they negotiate with hospital specialists to retain prescribing.

This role at the heart of the community may stem from the proximity of patients to the GP practice. GP4 commented that, although GMC guidance may imply that prescribing for a certain medicine would be better prescribed by a specialist, they may feel obliged to prescribe it themselves to avoid the patient having to make another journey to hospital. These requests may not always be acceptable to the GP. An example was given he was asked to prescribe a monoclonal antibody medicine to treat rheumatoid arthritis for a man struggling to attend the hospital to collect the medicine; yet the transfer request did not meet any of

the needs of the GP for information on safety and monitoring [GP6], therefore was turned down. This may be part of a wider situation of “GP dumping” which was mentioned during interviews. One GP [GP4] pointed out that such was the seriousness of the situation where tasks were being transferred to the GP without consideration of the impact, the Local Medical Committee had produced template letters for GPs to use when they felt they have been asked to take on prescribing outside the contracted agreements.

The concept of cradle to grave medicine was offered by one interviewee, exemplifying why she may be more likely to take on prescribing responsibility for supportive care in cancer treatment. By taking responsibility for a monthly injection, she is able to monitor the patient without causing any undue concern.

GPs were also aware that they were not the only professionals in a practice. Nurses are also bound by codes of practice, and therefore three GPs reported the need to confirm that a nurse is able to conduct a procedure before agreeing to take on the service on their behalf.

Two GPs demonstrated consideration of the professional role of the specialist, identifying that, although they may take responsibility for signing a prescription, having a clear care plan from a specialist would reassure them that something is the right decision to make. One GP indicated that his own practice had developed following requests from specialists to prescribe pramipexole in restless leg syndrome [GP4]. Another respondent provided the example of a letter she received from a neurologist that allowed her to manage a patient for over a year without difficulty; this resulted in “good feeling” for the patient as they felt like they were being “looked after”. [GP2] This may have been part of how she thought that patients differentiate between GPs (who are respected because of their long-term relationship with the patient) and hospital consultants (who provide a highly specialist expertise to the equation).

No two GPs or practices are exactly alike. One medicine (erythropoietin) was identified by two GPs as a specialist medicine that they had been asked to prescribe. For one GP, this was a medicine that she was unwilling to take on responsibility for, yet the other GP had been happy prescribing this for patients. This highlights the differences between individual GPs which may complicate development of policies that cover all scenarios. GMC guidance on prescribing across the interface recognises the individual nature of prescribers by leaving the decision to prescribe at the discretion of the individual based on their competence.

Most of the respondents reported administering luteinizing hormone releasing hormone (LHRH) agonists in their practice. These medicines come as both subcutaneous injections

and intramuscular injections, some of which have complex administration requirements. Despite the fact that these are often administered at long intervals (three months) practices have managed to incorporate this into practice safely and effectively. This may in part be due to the long time that these have been part of general practice, with one GP reporting that he thinks it's been happening since before he qualified 17 years ago, and as another reported, they were paid by the CCG to administer these.

### *Beliefs about capabilities (self-efficacy)*

The "beliefs about capabilities" domain seeks to address the way in which a professional thinks about how well they will be able to perform a task. The domain acts a bridge between knowledge and environmental factors (two other domains discussed here).

When discussing specialist medicines that require administration by a health care professional, interviewees indicated the need to have sufficient staff with the right skills to ensure the service can be delivered safely and in a timely manner.

*"We have to be confident about what we're doing and safety has to be paramount."* GP3

Considering administration of a subcutaneous injection within a practice, there was no suggestion from GPs that it would be impossible to do within the practice with enough staff and an appropriate skill-mix. Ability to deliver the service well may be a function of the frequency with which they repeat the task. One respondent gave an example of a service commissioned from GPs for fitting a contraceptive coil that required GPs to be performing a minimum of fifteen per year to provide the service. The rationale for this was to ensure quality of service and to keep failure rate to a minimum. This view was supported by another GP:

*"I'm of the opinion that we're always best doing something that we do fairly frequently."*

GP2

The respondent went on to explain that she didn't believe it would be appropriate for her to prescribe a medicine that she is likely only to encounter once in her career, though she highlighted that this wasn't a case of "can" she prescribe it, but rather "should" she.

There was a view that very little is really beyond the capability of the GP, so GPs need to be cautious about what they agree to take on.

*"I don't think there are many drugs that we wouldn't be able to monitor."* [GP4]

*“If you do a lot of reading and if you attend a lot of meetings ... you do become comfortable initiating some of these drugs.” [GP5]*

### **Beliefs about consequences**

This domain is linked to belief about capabilities and to knowledge. It focuses on the outcome that is expected, and can be influenced by an individual’s beliefs about punishment, rewards and regret.

GPs do not routinely prescribe chemotherapy; therefore, they may have no knowledge about drug-drug interactions with chemotherapy agents. One GP was more concerned about potential “consequences” when asked to prescribe *any* medicines for someone with cancer due to this lack of knowledge about interactions. Resultantly, the information provided to the GP should specify both the absence and presence of interactions with key medicines (e.g. “It is not anticipated that this medicine will interact with chemotherapy regimens”).

Potential serious adverse effects would be a great concern for a GP. Administration of a medicine where this can happen would require medical staff being available on site should a patient experience anaphylaxis.

*“Let’s say you would have a situation where a patient is booked in over lunchtime and ... there is no doctor on site and then something goes wrong. What do you do then?” GP1*

This concern underlines the difference between facilities available in a GP practice compared to a hospital. Another respondent highlighted that patients may not be happy about having a high-risk medicine administered in a GP practice if they don’t have the facilities to deal with them if something goes wrong.

*“When things go wrong they will go serious wrong ... you cannot initiate investigations and help quickly like in hospital.” GP6*

Consistent with the experience of the patients interviewed, one of the GPs showed an awareness that a consequence of asking patients to attend hospital for administration of a medicine will be submitting them to “a lot of waiting” [GP1]. This demonstrated that the consequences of *alternatives* are given appropriate weighting when making a decision.

A theme emerged from one interview that linked the GP’s knowledge with a belief about consequences. As new medicines are associated with uncertainty about emergent long-term side effects, devolving prescribing for these medicines to the GP would prevent a central

specialist from building knowledge and experience about the ADEs; additionally, a belief emerged that specialists would be more likely able to respond to ADEs more effectively.

### *Motivation & goals (intention)*

This domain combines both intrinsic and extrinsic motivations to perform an action. Examples of intrinsic motivation are the practitioners desire to prescribe, or their feelings that there is a need to prescribe. An extrinsic motivation might be existence of target or a financial reward. Motivations can be affected by the extent to which an intended action conflicts with other intended actions. [35]

The funding available for provision of a service was raised in several interviews. General practices operate as small businesses, and therefore have to be mindful of whether they are able to deliver the service within the resources available to their practice. However, this does not exclude the role of intrinsic motivation that drives delivery of patient care, and it was acknowledged that the financial benefit from providing some services may not be sufficient recompense for the work involved. None of the respondents suggested that a “financial incentive” to prescribe a specialist medicine (other than to ensure a service is adequately remunerated) would influence their decision making. This is consistent with a recent review of reviews, which found that financial incentives were ineffective at motivating long-term behaviour changes. [36]

*“We run quite a few things ... not because it makes us any money but because we want to look after our patients...” GP1*

*“...the patient feels looked after and supported because you’ve communicated well with the secondary care doctor.” GP2*

GPs are often required to ensure the spend on prescribed medicines stays within a budget. This was raised by one GP, who noted the need to be conscious about how the cost will be managed with more expensive medicines. Awareness of the cost and budgetary constraints surrounding a medicine, however, may frustrate GPs wanting to provide clinically appropriate care to a patient.

A negative motivating force identified by two GPs was the extent to which they feel that services were being dumped on them. As well as impacting on their “resilience” and ability to do a good job, there was a feeling that this transfer of responsibility was outside the arrangements of the current secondary care contracts.

### *Memory, attention, decision processes*

Prescribing medicines is a cognitive task that requires the clinician to access their memory and to make a coherent clinical decision. The prescriber must be satisfied that they will remember to carry out all the steps necessary to safely prescribe a medicine (e.g. conduct all the required monitoring). Implicit in this is a consideration of whether the prescriber will find opportunity to give a task appropriate attention.

Two examples of the importance of this in general practice that were raised during the interviews were prescribing of methotrexate (a commonly used immunosuppressive treatment) and novel anticoagulants.

*“Methotexate: what do I do? I simply do a prescription and then we have somebody who checks that the blood tests are done in regular intervals.” GP1*

*“Another good example: haematology because they send you, when they start someone on anticoagulation, this new kind of pro-forma ... I know what my expectations are for me.” GP2*

These anticoagulation communications provided information in an anticipatable way, so removed some of the responsibility of the GP to remember the monitoring schedule, thus facilitating the decision-making process when taking on prescribing responsibility. [GP2]

This suggests that the way in which a request to prescribe a medicine is made can impact on the ease with which a GP can say yes; by reducing the amount of cognitive effort that is required, specialists may be seen to be recognising the needs of GPs. There may be a role for IT systems to support this, though as has already been discussed, this may be limited. [37]

### *Environmental context and resources*

This domain recognises that decisions have to be made taking into account the systems that operate around us, and the individual characteristics and features of the place in which we work.

The ease with which blood tests are available has been described as contributing to the decision process (see above). This also features as a component of the Environmental Context in which the GP operates; if the GP is aware that the systems in place make it difficult to access blood results, it may impact on their willingness to accept prescribing responsibility for a medicine.

For example, patients requiring regular ongoing administration of a medicine would need to be called back to the practice for further doses. None of the GPs interviewed described an IT system capable of booking appointments more than a month in future, relying on patients to remember to book appointments at the appropriate intervals. The seriousness of

consequences should a patient not remember to attend for an appointment would have to be taken into account when deciding if a medicine can be prescribed. Research has been shown that GP IT systems can provide some limited support to help GPs avoid errors when prescribing specialist medicines. [37]

GP practices differ in the number of GPs, the number of simultaneous clinic rooms operating, and in the number of nurses employed. These differences can have a significant impact on a GP's willingness to take on prescribing and/or administration responsibility for a particular medicine. Not all practices are able to recruit practice nurses, which impacts on GP workload and may make them less likely to take on medicines administration services.

One GP highlighted that even well-designed systems may breakdown, which is important when considering capacity to take on new services. An example of methotrexate booklets (used to communicate monitoring between the specialist and the GP) was given; patients aren't always "interested" in making sure these contain the necessary information to support a GP to prescribe [GP1]. Furthermore, consideration was given to the IT infrastructure that communicates blood results between the hospital and GP practice. Not all hospitals have computer systems capable of communicating blood results directly with the GP. One respondent [GP2] gave an example of the ease of reviewing blood results from a hospital which posts results directly to the GP's system, compared to another hospital that uses paper-based order forms; the difference in ease of monitoring a patient may impact on the GP's decision to take on prescribing.

GP practices may not have sufficient rooms available for administration of infusions that were likely to take a period of time. Without multiple trained staff members available in the practice, it would not be possible to monitor patients during the infusion without taking staff away from other duties.

Familiarity with the support systems available to GPs was important. The example of administration of antipsychotic depot injections was given by one GP, as the service allows her to refer a patient back to the Mental Health team if they miss one or two appointments; this provision reassured GPs that they were not on their own in caring for patients when they take on responsibility for new roles.

### ***Social influences (norms)***

GPs, like all humans, are social animals, and are therefore influenced by social norms. These can come in the form of GP colleagues, health care managers, other health care

professionals and patients. As identified by Michie *et al*, social influences can manifest through a wide variety of mediums (see Appendix 6: Michie Domains [full details] for examples). [24]

Two influential social groups identified during this research were the wider practice team, and CCG Medicines Management Teams. Discussions with other staff within the practice ranged from questions about appropriateness of taking on prescribing (discussions with other GPs), to planning delivery of a service (discussions with GPs and nurses). Medicines Management Teams, groups of pharmacists responsible for directing local prescribing policy, were identified as sources of clinical and policy information, with the implication that what they recommended was an expected social norm that should be followed.

Influences from wider NHS policy impact on GP behaviour. For example, one GP with a knowledge of the commissioning process, identified the “organisational climate” of the NHS and reported that the idea of delivering cancer supportive care to patients in primary care was part of the direction of travel, for example through stratified follow-up of prostate cancer patients. Though she explained that this does not mean that every GP practice should be upskilled to deliver all elements of this care; instead certain individual clinicians will be able to deliver a truly holistic care service to people with cancer. This organisational development is part of an aim to be responsive to the needs of people with cancer (and indeed other long-term conditions) by providing large elements of their care in one setting.

Agencies like NHS Business Services Authority (monitoring prescribing) and the Care Quality Commission (regulating quality of service) were recognised as other influences that are in the GPs mind when they are thinking about which medicines they are able to prescribe.

### **Emotion**

The original framework considered the impact of both positive and negative emotions on a professional’s likelihood to adopt evidence based practice. The research identified where respondents described an emotion, considering whether this emotion was caused by the situation, or was hindering or supporting a practice.

The emotional words used by the interviewees were largely negative: disheartened, embarrassing, frustrating, anxious, annoyed. This indicated that the GPs were operating within a challenging emotional environment. One respondent expressed that she was aiming to feel comfortable that what she was doing was safe when she made a prescribing decision. Feeling uncomfortable when reviewing a prescribing decision that someone else has made is not unique to GP; research into hospital doctors identified a similar emotion, as a prescriber

is not always aware that they are in possession of all the facts that the original decision maker had. [38]

### ***Behavioural regulation***

This domain of the framework addresses the steps that can be taken to support or encourage adopting a particular behaviour. This could be in the form of target setting, action planning, and moderators of the intention-behaviour gap.

Discussion about shared care agreements would fit into this domain, as these documents are designed to facilitate a GP to get from wanting to prescribe a medicine to actually prescribing it. As discussed above, these documents achieve this by linking in with other domains (such as addressing a knowledge gap). They also provide a link back to specialist practitioners, thus ensure GPs are supported when prescribing specialist medicines.

One respondent linked this domain to environmental factors, highlighting that introducing alternative ways of working (e.g. speciality clinics in the community) would produce an environment through which delivery of specialist care can be achieved.

### ***Nature of the behaviours***

This domain explores the extent to which a behaviour can become a routine or a habit. This domain links with the response discussed under beliefs about capabilities above that expressed a belief that GPs should focus their attention on jobs that they perform often. It is through repetition of a task that we can demonstrate mastery.

*“I’m of the opinion that we’re always best doing something that we do fairly frequently.”*

GP2

## Patient Interviews

Interviews were conducted with four patients, two of whom attended with a carer. Carers were invited to contribute during the interviews. Each interview was scheduled to take 60 minutes; the actual duration ranged from 20 minutes to 70 minutes.

All interviews were analysed using Tsianakas’s framework of “Moving through the system”. [24] The transcripts were coded against the six domains identified below. Each domain was represented in all four patient interviews, with the exception that Patient 2 did not mention “Administrative issues” and Patient 4 did not mention “Communication”.

## Framework Analysis

Framework domain	Interview themes
Waiting time	<ul style="list-style-type: none"> <li>• Waiting for physical space to administer therapy</li> <li>• Impact of knowing how long procedure takes once have waited</li> <li>• Waiting several times in different areas</li> <li>• Waiting seen as “one-sided”</li> <li>• Waiting implies there isn’t time to raise other issues</li> <li>• Impact of waiting on rest of life</li> </ul>
Administrative issues	<ul style="list-style-type: none"> <li>• Co-ordinating appointments during the day</li> <li>• Keeping on top of staff to make sure all aspects of care are covered</li> <li>• Recognising a failure in the “check in” process</li> <li>• Ease to book an appointment</li> </ul>
Continuity of care	<ul style="list-style-type: none"> <li>• Different person administers each time</li> <li>• Less important to build relationship than it is for chemotherapy</li> <li>• Confidence and safety in administration is more important</li> </ul>
Front-line staff	<ul style="list-style-type: none"> <li>• Friendly staff administering treatment expected and received</li> <li>• Building relationship with reception staff improves experience</li> </ul>
Speed moving through system	<ul style="list-style-type: none"> <li>• Links with “Waiting time”</li> <li>• System can breakdown due to need for blood tests, lack of prescription or due to workload of the clinic</li> <li>• Self-administration could facilitate system improvement</li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Need to find a way to communicate clinic delays with patients, e.g. text messages</li> <li>• Communicating instructions for appointment system and patient portal identified as area for improvement</li> <li>• Fear that communication between two hospitals might fail (if receiving administration remotely)</li> <li>• Need to find way to share blood results so can have these done away from cancer centre if long way to travel</li> </ul>

Figure 4: “Moving through the system” results from patient interviews

### *Waiting time*

There was no specific question in the interview schedule about waiting times, yet this theme was present in all four interviews. There was a recognition from patients that you were going to be waiting for each aspect of your care, with “the best” experience being described by three patients as one in which things run to a smooth schedule and the injection is administered quickly.

Three respondents made it clear that waiting in a busy teaching hospital was not necessarily a problem, but it was obvious that this waiting time would have an impact on their lives, with a recognition that denosumab treatment days do not allow time for anything else to happen. A sense of injustice was vocalised by one patient, who pointed out that although the clinicians could be running late, if a patient was running late they would miss their slot. However, this was not backed up by another patient who said that the ambulatory care clinic would see patients regardless of the time they had originally arranged to have their denosumab.

*“You’ve got an appointment for 10.30, but if you don’t get there, you might lose that appointment because you’re late.”* Patient 3

*“If there’s a hold-up in clinic then you obviously arrive for the denosumab injection late as well.”* Patient 1

Each of the interviewees commented on the amount of time waiting, with variable emotion.

*“It’s fine, I’m retired, I always have a book or some sewing and it’s no problem for me at all...”* Patient 4

One patient was sympathetic towards the system despite a miscommunication about the need for a blood test having resulted in an extended wait in the hospital.

*“I don’t mind it’s just a bit of a nuisance when you’ve got to hang about for three hours, but, nevertheless, it’s not the end of the world.”* Patient 2

Interviewees were largely sympathetic to the “busy” circumstances within which the nurses were operating, reporting that they felt the staff did a very good job. There was, however, criticism of the system where waiting seemed to be the product of poor planning or a breakdown in the process. Frustration, however, was raised that the long waits were for what was essentially a very quick injection:

*“So waiting, in itself, in a busy teaching hospital is not really a problem, I think people are prepared to wait, but when you wait three times for something that takes two minutes, and I’ve been here two hours already ... that is really frustrating.” Patient 1*

*“The thing that frustrates me most is waiting... It our appointment is at 11.30, then two hours is unacceptable.” Carer 3*

Though the people interviewed did not seem to resent the amount of time waiting, it should be noted that none reported having any current work or family commitments that might make their time more critical. One respondent mentioned that although waiting was not a problem for her, it was a problem for the family member who brought her to the hospital.

Long waiting times overlapped with administrative issues experienced by patients. One patient described a failure in the administrative process when checking into receive denosumab that resulted in a two-hour delay before she was scheduled to receive denosumab. That this delay did not get spotted by either the patient or administrative staff earlier suggests that long waits in the ambulatory care unit were not out of the expectation of either patient or staff.

#### **Administrative issues**

These were described as failures in the system to co-ordinate appointments, or for the system to flow as intended. The themes highlighted in the research were similar to those identified by Tsianakas *et al* [24] in that there was an implicit expectation from the patient that they would lead to a negative experience of the service. For one respondent, the administrative issues were considered upsetting when taken in the context of the overall great care she felt she received:

*“...All my bugbears are about the administrative stuff, none of it is about any of the medical care... which is all ... world class, it’s brilliant.” Patient 1*

There was a feeling that, although you agree an appointment time to attend the Cancer Centre to see the consultant, treatment with denosumab, which always happens subsequent to this initial appointment, was not according to any scheduled appointment time because delays waiting for the consultant had an inevitable impact on subsequent treatment. Thus, booking an appointment time to receive denosumab seemed an unnecessary step, which added an element of uncertainty onto the patient who was asked to estimate how long they think it would be before they moved through the system and

were ready to receive denosumab. One patient suggested it would be just as efficient if the clinic operated with a list of patients who were likely to attend on any given day.

*“I think they [the clinic where denosumab is administered] know what it’s like so I think people are always turning up at random times, so you just, kind of, join the queue pretty much whatever time you get there, however late you are.”* Patient 1

When asked about receiving denosumab in another setting, one patient based their assessment of the suitability of the GP surgery on the ease of booking appointments online, indicating a preference for administrative systems that are easy to navigate.

### **Continuity of care**

Tsianakas *et al* [24] reported that the only element of continuity of care that patients valued came from building a trusting relationship with doctors and nurses by seeing the same health care professional each time. Although this was a key touchpoint for patients, they noted that none reported the importance of continuity of care between departments.

Conversely, this research identified that patients were not as concerned about receiving their treatment from the same person each time, indeed, when it was raised in the interviews the consensus was that this had never happened before, therefore was not expected. One respondent did not believe it was as important to build a relationship with your denosumab nurse because it was such a quick injection (compared to chemotherapy) that it was irrelevant.

Two interviewees highlighted that they would prefer not to have denosumab administered at the Cancer Centre to make it easier for them to get to the appointment, with neither highlighting that they thought the relationship with the person administering the medicine was a key component of care.

### **Front-line staff**

Similar to previous research, this evaluation identified the positive impact gained from friendly front line staff. The words used to describe the staff at this Cancer Centre were very positive: “lovely”, “smiling”, “helpful”, and “friendly”.

*“I couldn’t praise enough the people here, I think they are amazing, they work very hard...”*  
Patient 2

When answering the question about the best treatment experience, Patient 3 was more concerned about the warmth of the care she received from the people administering denosumab than she was about waiting times.

These reports of great care were despite the comments above related to respondents wishes to receive their denosumab elsewhere, indicating that their decisions were not based on the way they were treated by staff at the centre.

### *Speed moving through system*

For Tsianakas *et al*, [24] this domain focussed on the speed at which patients moved from diagnosis to treatment, yet it was considered relevant to the current analysis because the speed with which someone moves through the system on a daily basis is relevant to the patient's experience of their care. As with the research by Tsianakas *et al*, this concept was closely related to waiting time, which was presented above.

Again, although the majority view was that once you were ready to have the treatment administered it would be a very quick process, however, the system seemed usually to move slowly to get to that point. Interviewees mentioned different aspects of their care that resulted in this, such as a delay getting a prescription, blood tests not being ready, or staff being too busy to administer denosumab at the agreed time.

The ease with which patients perceive denosumab is administered was likely to have been responsible for a blasé attitude to the options proposed to make the system work better. For example, one respondent suggested a nurse could “pop in” [Patient 1] to the clinic room to administer denosumab after the doctor has finished their review.

*“It literally takes 30 seconds to give the injection, maybe two or three minutes for them to load the [syringe].”* Patient 1

Another patient identified that she had been asked whether she would like to self-administer denosumab, which she felt would be a good way of supporting a reduction in nurse workload.

### *Communication*

As with the work by Tsianakas *et al*, communication proved to be a topic that generated a lot of consideration. In their EBCD work, communication was identified as a priority area for improvement, specifically looking at communication between patients and staff, having enough time to talk with staff, provision of written information, and knowing what will happen next.

Similarly, this evaluation found that patients want to be kept advised of progress, specifically on the day of denosumab therapy when delays in clinics may provide the time to adjust their schedule, either by arriving later or by finding something else to fill their time, for example find lunch, go to one of the local shops, or turn up later.

*“... if there’s an hour here waiting to see a consultant, one text, ‘Running an hour late,’ we’d leave half an hour later.”* Carer to Patient 3

This proposal to utilise information technology to improve the experience of patients continued in another suggestion the carer had to allow two-way communication via the “Patient Portal” so they could have blood tests taken closer to home and then communicate them with the consultant. This was suggested as it would have the benefit of preventing unnecessary visits to the hospital if blood results preclude treatment. Blood test are an essential part of denosumab therapy and were resultantly identified as a touchpoint in the patient pathway at UCLH. Their impact on patient experience is important to consider.

Two patients specifically mentioned their Clinical Nurse Specialist as a potential source of communication between patients and the hospital.

### **Touchpoints at University College London**

The first four questions in the interview schedule (see Appendix 5: Patient Interviews Protocol) were included in order to elicit the different touchpoints in a person’s treatment pathway on the day of denosumab administration.

The process described varied slightly between the patients, though each involved seeing a consultant, having blood taken and receiving a denosumab injection. One patient also described seeing a pharmacist, and a second included waiting at the pharmacy for their calcium supplement (take home medicine) to be dispensed. One patient was also receiving chemotherapy, therefore included waiting for this to be produced and subsequently receiving her dose. At each of the different stages of the day when receiving denosumab treatment, waiting was highlighted as a common theme as described above.

Exploring a patient’s full experience of a specific aspect of care has been used to highlight aspects of the process that the people who designed a system were not aware of. There are certain experiences that only a patient using the system is able to describe adequately because, unlike health care professionals who only see a small part of the system, they follow the whole process. [17] This research has highlighted that patients follow an approximately similar process through the system, and has highlighted that the main problem with the system is the amount of waiting required of the patient. Taking a term from design science, this can be explained as a system that achieves “performance” and “engineering”, but fails to meet patient expectations of “aesthetics”. [17]

## Other themes emerging from patient interviews

### Travel

All interviewees were asked about their journey to the Cancer Centre on the day of the interview, and were asked to consider how this compared to a typical day when they received denosumab. Two of the respondents relied on public transport, one respondent travelled in private transport with her husband, and a fourth respondent relied on family members to bring her, or to use a taxi.

The two respondents using public transport were generally more positive about the experience than those using private vehicles. This may have been a function of the simplicity of their journey, as they both reported living close to the cancer centre.

*"It's very quick, about 20 minutes from door to door."* Patient 1

*"Oh, it was very easy... It takes me 20 minutes."* Patient 4

Public transport was not an option for Patient 2, who relied on family members to bring her, although she lived relatively close to the hospital. This extended to challenges in being able to pick up a taxi.

The fourth patient chose to travel approximately twenty-five miles to get to the UCLH Cancer Centre despite there being alternative treatment centres closer to home. Each journey for her lasted between forty and seventy minutes depending on traffic conditions. She acknowledged there were public transport options available, including a fast train, but preferred to be driven by her husband due to her "impaired immune system". This interviewee highlighted frustrations of travelling by car that included traffic volumes and difficulties finding a parking space near the hospital; the latter had been exacerbated by recent extensive building work around the hospital.

When discussing her travel to the hospital, Patient 3 noted that she was "lucky" that her son was able to bring her to her appointment on this day, though she expressed anxiety about how she would be able to attend the hospital for this and other appointments in the future as her son did not live in London.

During the interview with Patient 4, her carer pointed out that it was only because he was now retired that they had the option to travel to central London for any of her care. They were quick to point out that there was an element of "luck" in this situation, and that they recognised that "not everybody is in our position."

It is clear that administration of supportive therapy to people who have had cancer can have a large impact on their lives. Considered together with the discussions above about waiting times, design of the service should take this impact into account.

#### *Additional considerations specific to administration of the medicine*

There was a link between being able to administer denosumab competently and frequency with which an individual administers the drug. One respondent highlighted that it would be an efficient use of resources to have someone administering only denosumab, thus would be able to demonstrate excellent competency at this, and would not be distracted by other tasks.

Two interviewees were of the opinion that denosumab could be administered anywhere as it is such a simple injection. A third interviewee thought that the Cancer Centre was the most appropriate place to administer denosumab because the “clean and sterilised” environment provided her with reassurance that she would be safe. Two interviewees commented on the need for privacy, as it is necessary to expose the stomach in order to administer denosumab. All four interviewees were of the opinion that the GP practice would be a suitable place to receive their denosumab, citing proximity of the practice to home and the simplicity of the injection as significant reasons. The strength of the appointment booking system at one patient’s GP practice, which was in contrast to the stated view about the hospital appointments system, was quoted as a major factor for favouring attending there for administration of denosumab. However, she continued by explaining that, as the denosumab administration schedule fits with the schedule of specialist appointments at the hospital, she could see no reason for going to her GP for treatment.

One patient proposed that she might consider administering it herself if she was given the option, and a second patient agreed that this might be something she’d consider if given the option. The reasons for these views were speed and seeming ease to administer the (subcutaneous) injection. The importance of involving patients in elements of their care where they want to was considered; the benefits in terms of staff time and patient travel time were highlighted. A third respondent did not feel that self-administration of denosumab at home was a suitable option for her, stating that she would “like to be in a safe place” for her medicines to be administered.

A final option, proposed by an elderly respondent who lives close to the hospital, was for a district nurse to come to administer denosumab. This option was favoured because the respondent found it difficult to get out of the home to attend the Cancer Centre.

## Discussion

Five domains emerged as dominant themes describing the barriers and enablers experienced by GPs when prescribing specialist medicines: knowledge, social & professional roles, beliefs about capabilities, beliefs about consequences, and environmental context & resources. These themes were largely consistent with those identified through a systematic review of papers describing the barriers and enablers experienced when clinicians consider stopping potentially inappropriate medicine: awareness of the problem (knowledge), self-efficacy, and feasibility (environmental context) were key concerns when attempting to stop medicines. [39]

Multiple factors were identified that impact on a GP's decision to take on prescribing and it should be remembered that prescribing is not a purely technical process. [40] Although the framework described in this research uses twelve domains, previous authors have categorised the influences in two groups: internal factors (e.g. past experience, professional confidence) or external factors (e.g. information received from the health authority or professional peers). [13]

Clinicians and health services managers responding to this research should focus their attention on ensuring the external factors are addressed, for example through provision of documentation that clearly addresses GPs' knowledge needs, in addition to ensuring the political environment is appropriate to provide the care. As was identified in this research, consultant prescribing behaviour is also a source of education for GPs; Armstrong and Ogden (2006) suggested that a way should be found to harness this learning opportunity in a way that can support others to innovate their practice. [23] A systematic review of interventions to improve prescribing identified that educational outreach together with audit and feedback is often sufficient to influence prescribing, but there is a need for more robust research to understand whether this kind of intervention will be universally effective when trying to influence prescribing. [41]

In London there is a well-established reliance on the provision of information from pharmaceutical advisors employed by CCGs, and the area prescribing committee formulary, which can provide reassurance to GPs of the local acceptability or desirability that a particular treatment be prescribed. As surveys of doctors have demonstrated that there is a preference for receiving information from people (as opposed to written information), [42]

it would seem likely that pharmaceutical advisors could be harnessed as a positive influence when looking to support primary care prescribers adopting innovative evidence based interventions. Indeed, this professional group is able to communicate the “social norms” of prescribing policy within a local health economy, which has been found to be an important step in influencing prescribing behaviour change. [43]

Many health services are built around the system in which they are operating, rather than being designed around the service user, with the unfortunate consequence that an efficient system may not offer a very good experience for the patient. [16]

Patients at UCLH MacMillan Cancer Centre had mixed attitudes towards the implications of waiting in hospital, and reported communication issues. Frustrations were raised about administrative issues or poor technological infrastructure that impacted negatively on their experience of care. Although patients were largely positive about the personal element of the care they received at the hospital, the majority of respondents were open to the idea of receiving their denosumab injections away from the hospital (e.g. from GP, district nurse, or by self-administration). Similar to previous commentary, [20] this evaluation found that the patients interviewed were willing to share their experiences and could describe the key “touchpoints” that affected their care in order to support service development. [25]

## Limitations

It is well recognised that qualitative research doesn’t aim to achieve a “representative” sample. [30] There is potential bias in that those who did not choose to participate in the research held views or had experiences that were substantially different from those of the research participants.

A small number of patients were included in this evaluation. Although previous research into the benefits of patient-partnerships for redesign of cancer services has had favourable experiences when recruiting patients to participate, there were a number of recruitment challenges experienced, which could be addressed in the future by utilising the relationships patients have established with health professionals within the service to increase recruitment.

This research does not take the patient interviews to the next stages of experience-based co-design. Future research could address this.

The interviews of patients were undertaken as an evaluation of the service delivered by UCLH Macmillan Cancer Centre, therefore the findings may not be applicable more widely.

## Conclusions

This research explored and reported the experiences and views of two stakeholders in the provision of cancer supportive care in community: GPs and patients.

GPs have numerous concerns about taking on specialist medicines which need to be taken seriously. Staff working in hospitals can address knowledge needs, but engagement with commissioners is needed to address the environmental context within which GPs operate. Commissioners and medicines policy decision makers also need to consider carefully whether general practice is the appropriate place for administration of some specialist medicines. Exploration of use of specialist community clinics might be more appropriate.

Patients were largely open to the idea of receiving their denosumab injections away from the hospital. Future research with patients in this clinic could employ the later stages of evidence-based co-design by recruiting panels of patients, clinical staff and managers to discuss the touchpoints described and collaboratively identify opportunities to improve the service.

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## Appendix 1: Patient Information Leaflet

### **What is the purpose of this project?**

This project is designed to understand what people receiving denosumab therapy think about the current arrangements for the service, to help us find out if there is anything we could be doing better.

### **Why have I been chosen?**

You have been selected to take part because you are receiving a medicine called denosumab (also known as Xgeva®). We really want to understand the experiences of patients receiving this medication.

### **Do I have to take part?**

No. If you do not wish to take part, there is no need to respond to this request. You do not need to provide a reason and it will not affect the care you receive.

### **I would like to take part. What should I do?**

You can either send an email to [john.minshull@uclh.nhs.uk](mailto:john.minshull@uclh.nhs.uk) or send a letter to John Minshull, UCLH Pharmacy Department, 250 Euston Road, London NW1 2PG. Please just say that you're interested and provide a contact number or address. A researcher will then contact you to arrange a convenient time for the interview. The interviewer will try to arrange the interview on the same date that you receive your denosumab injection to make it more convenient for you. Keep hold of this information sheet. On the day of the interview, please bring along a signed copy of the consent form enclosed. You are able to withdraw consent at any point, even during the interview. You do not need to give a reason for this.

### **Can my carer share their experience as well?**

Yes. We would really like to interview you separately to get as much information as possible, but it may also be possible to conduct the interview at the same time. Please discuss this with the research when they call to arrange the appointment.

### **What happens during the interview?**

The interviewer will ask you questions about your experience of receiving denosumab therapy. They have some questions to help you tell your story. It is important that you tell the story in your own words. The interview will take approximately 60 minutes, but it will be tailored to fit around your availability. The room will be private, so what you discuss will not be overheard by anyone.

The interviewer will use an audio recorder to record the interview. This will allow the interviewer to listen to you during the interview, without having to write down everything you say. This recording will not be shared with your clinical team and it will be destroyed once an anonymous transcription has been made. All personal information (e.g. names, places) will be removed.

### **Who will hear the recording?**

Two people will hear the audio recording. The first is the person conducting the interview. A second person employed to type up the recording will also hear it. Both of these people will be bound by a Confidentiality Agreement, so they will not share your information with anyone else.

**What happens to the information people tell us?**

A report will be written based on the information received during your interview and the other interviews that are taking place. Your interview will be one of approximately ten interviews with patients. The report will be shared with local health care staff and managers. All personal information will be kept anonymous, so there is no way anyone reading the report will know who said what.

The findings of our service evaluation will be shared more widely with health care staff across the country that work in this field to help them understand what we are doing to improve our service.

**Will I know the interviewer?**

No. The interviewer is a pharmacist who works for University College London Hospital, but they will not have been involved in your care.

**Where will the interview happen?**

The interviewer will prepare a comfortable, private room in the University College London Hospital Macmillan Cancer Centre.

**What is something goes wrong during the interview?**

If the interviewer hears something during the interview about your treatment that concerns them, they will speak to you about this after the recording has ended.

If you tell the interviewer something that suggests you have received unacceptable or unsafe practice, they will be required to report this. This is because NHS staff are required to ensure that every patient is kept safe. In the unlikely event that this happens during the interview, the interviewer will discuss it with you after the recording has ended.

**Who is organising this project?**

This project has been organised by a pharmacist working for University College London Hospital. The project is supported by a research grant from the British Oncology Pharmacists Association.

**Who has approved this project?**

UCLH Cancer Division

**Adapted from** South East Wales Cardiac Network. Taking Part in Discovery Interviews. Frequently Asked Questions.

## Appendix 2: Patient Informed Consent

**Please complete this form after you have read the Information Sheet provided.**

**Project Title:** Interviews with people receiving denosumab therapy at UCLH Cancer Centre

**Researcher:** John Minshull

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Frequently Asked Questions or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

### **Participant's Statement**

I agree that:

- I have read the notes written above and the Frequently Asked Questions sheet provided, and I understand what the study involves.
- I understand that my participation will be audio recorded and I consent to use of this material as part of the project.
- I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- I consent to the processing of my personal information for the purposes of this research study.
- I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- I understand that the information I have submitted will be published as a report. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signature:

Date:

## Appendix 3: GP Informed Consent

**Please complete this form after you have read the invitation letter provided.**

**Project Title:** Interviews with General Practitioners about prescribing and managing new medicines

**Researcher:** John Minshull

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the invitation letter or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

### **Participant's Statement**

I agree that:

- I have read the notes written above and the Frequently Asked Questions sheet provided, and I understand what the study involves.
- I understand that my participation will be audio recorded and I consent to use of this material as part of the project.
- I understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- I consent to the processing of my personal information for the purposes of this research study.
- I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- I understand that the information I have submitted will be published as a report. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- I understand that confidentiality between other members of the group interview will not be possible to achieve.
- I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

**Signature:**

**Date:**

## Appendix 4: GP Individual Interview Protocol

- Welcome the **interviewee** by name and thank them for agreeing to take part in the research
- Remind the interviewee that they are free at any point before, during or after the interview to withdraw their consent. If they choose to stop the interview part way though, they can ask that the recording be deleted
- All recordings and written notes will be anonymous, so you cannot be identified individually
- Make sure they are comfortable and remind them that the interview will take approximately an hour
- Explain that you have a number of questions to ask. There are no right or wrong answers, because the aim is to understand your experience of your treatment.
- Most important is that they tell their story in their words
- Make sure have signed consent forms for the participant

### Questions

All questions will be relating to the prescribing of new or specialist medicines. When I say **new** medicine, I mean any medicine that is not part of your everyday practice. The drug may not be new to the market.

1. Thinking back to the last time you were asked by a hospital specialist to prescribe a drug you were unfamiliar with, what decision did you make? Why?
2. Do you think there are medicines that are not suitable for a GP to prescribe?
  - a. If yes, what characteristics would they have?
3. What are the best experiences you've had when you've been asked to prescribe a new drug?
4. What are the worst experiences you've had when you've been asked to prescribe a new drug?
5. What different players are involved in a decision to prescribe a medicine you're unfamiliar with?
  - a. Do any of these players have a stronger role in the decision making?
6. If you were asked to prescribe and administer a monthly, subcutaneous injection in to a patient, what considerations would you have?
  - *Acknowledge that there is a specialist drug in mind with this questions:*  
denosumab 120mg in 1.7mL
7. If the patients requiring this drug had a diagnosis of cancer, would you have any other considerations?
8. Are there any other injectable medicines that you routinely prescribe / administer. What is it about these that caused them to prescribe?
9. Is there anything else you would like to add?

### Timings:

Welcome (5 minutes)

Questions (53 minutes)

Conclude (2 minutes)

**Note time started:**

## Appendix 5: Patient Interviews Protocol

- Welcome the **interviewee** by name and thank them for agreeing to take part in the research
- Remind the interviewee that they are free at any point before, during or after the interview to withdraw their consent. If they choose to stop the interview part way though, they can ask that the recording be deleted
- All recordings and written notes will be anonymous, so you cannot be identified individually
- No identifiable information will be shared with your clinical team, except if there is something that you say which causes me concern. This has been mentioned in the FAQ.
- If you have any questions about your individual care, you will need to speak with a nurse, pharmacist, or doctor who is familiar with your care
- Make sure they are comfortable and remind them that the interview will take approximately an hour
- Explain that you have a number of questions to ask. There are no right or wrong answers, because the aim is to understand your experience of your treatment.
- Most important is that they tell their story in their words

### Questions

All of the questions will be relating to an injectable medicine that you receive called denosumab. Some people know this medicine as Xgeva.

1. Can you tell me about your journey here today?
  - a. *How did this differ from other days when you've come for denosumab?*
2. Can you tell me about a **typical** day when you have denosumab treatment?
3. Can you think of the best experience you've had when receiving denosumab treatment?
4. Now tell me about the worst experience you've had?
5. What do you think are the key characteristics of someone giving denosumab treatment?
  - a. *Do you think this has to be a certain type of health care professional?*
6. What do you think are the key characteristics about where denosumab treatment should be given?
7. What do you think could be changed to make this a better experience for you?
  - a. Would you prefer to receive denosumab at your GP?
  - b. Would you prefer to receive denosumab at home?

## Appendix 6: Michie Domains [full details]

Domains	Constructs	Interview questions
1 Knowledge	Knowledge Knowledge about condition / scientific rationale Schemas + mindsets + illness representations Procedural knowledge	What do they know about the medicine? What do they think the evidence is?
2 Skills	Skills Competence / ability / skill assessment Practice / skills development Interpersonal skills Coping strategies	Do they know how to prescribe the medicine? Do they know how to monitor the medicine? How easy or difficult do the find prescribing and monitoring the medicine to the required standard in the required context?
3 Social / professional role and identity (self-standards)	Identity Professional identity / boundaries / role Group / social identity Social / group norms Alienation / organisational commitment	What is the purpose of the medicine? What do they think about the credibility of the source informing them? Do they think recommendations to prescribe should determine their behaviour? Is prescribing the medicine compatible or in conflict with their professional standards / identity? (prompts: moral / ethical, limits to autonomy) Would this be true for all professional groups involved?
4 Beliefs about capabilities (self-efficacy)	Self-efficacy Control – of behaviour and material and social environment Perceived competence Self-confidence / professional confidence Empowerment Self-esteem Perceived behavioural control Optimism / pessimism	How difficult / easy is it for them to prescribe the medicine? What problems have they encountered? What would help them? How confident are they that they can prescribe the medicine despite the challenges? How capable are they of prescribing the medicine in an ongoing manner? How well equipped / comfortable do they feel to prescribe the medicine?
5 Beliefs about consequences (anticipated outcome and attitude)	Outcome expectancies Anticipated regret Appraisal / evaluation / review Consequents Attitudes Contingencies Reinforcement / punishment / consequences Incentives / rewards Beliefs Unrealistic optimism Salient events / sensitisation / critical incidents Characteristics of outcome expectancies – physical, social, emotional Sanctions / rewards, proximal / distal, valued / not valued, probable / improbable, salient / not salient, perceived risk / threat	What do they think will happen if they do x? (prompt re themselves, patients, colleagues and the organisation; positive and negative, short term and long term consequences) What are the costs of x and what are the costs of the consequences of x? What do they think will happen if they do not do x? (prompts) Do benefits of doing x outweigh the costs? How will they feel if they do/don't do x? (prompts) Does the evidence suggest that doing x is a good thing?
6 Motivation and goals (intention)	Intention, stability of intention / certainty of intention, Goal (autonomous, controlled) Goal target/setting Goal priority Intrinsic motivation Commitment Distal and proximal goals Transtheoretical model and stages of change	How much do you want to prescribe the medicine? How much do you feel you need to prescribe the medicine? Are there other things you want to do or achieve that will interfere with you prescribing the medicine? Does the recommendation to prescribe this medicine conflict with other guidelines? Are there any incentives to prescribe the medicine?
7 Memory, attention and decision processes	Memory Attention Attention control Decision making	Is x something they usually do? Will they think to do x? How much attention will they have to pay to do x? Will they remember to do x? How? Might they decide not to do x? Why? (prompt: competing tasks, time constraints)
8 Environmental context and resources (environmental constraints)	Resources / material resources (availability and management) Environmental stressors Person x environment interaction Knowledge of task environment	To what extent do physical or resource factors facilitate or hinder x? Are there competing tasks and time constraints? Are the necessary resources available to those expected to undertake
9 Social influences (norms)	Social support; Social / group norms	To what extent do social influences facilitate or hinder

Domains	Constructs	Interview questions
	Organisational development Leadership; Team working Group conformity Organisational climate / culture Social pressure; Power / hierarchy Professional boundaries / roles Management commitment Supervision; Inter-group conflict; Champions Social comparisons; Identity; group / social identity Organisational commitment / alienation Feedback; Conflict – competing demands, conflicting roles; Change management Crew resource management; Negotiation Social support; personal / professional / organisational, intra/interpersonal, society/community Social / group norms: subjective, descriptive, injunctive norms Learning and modelling	x? (prompts: peers, managers, other professional groups, patients, relatives) Will they observe others doing x (i.e. have role models)?
10 Emotion	Affect Stress Anticipated regret Fear Burn-out Cognitive overload/tiredness Threat Positive/negative affect Anxiety / depression	Does doing x evoke an emotional response? If so, what? To what extent do emotional factors facilitate or hinder x? How does emotion affect x?
11 Behavioural regulation	Goal / target setting Implementation intention Action planning Self-monitoring Goal priority Generating alternatives Feedback Moderators of intention-behaviour gap Project management Barriers and facilitators	What preparatory steps are needed to do x? (prompt re individual and organisational) Are there procedures or ways of working that encourage x?
12 Nature of the behaviours	Routine / automatic / habit Breaking habit Direct experience / past behaviour Representation of tasks Stages of change model	What is the proposed behaviour (x)? Who needs to do what differently when, where, how, how often and with whom? How do they know whether the behaviour has happened? What do they currently do? Is this a new behaviour or an existing behaviour that needs to become a habit? Can the context be used to prompt the new behaviour? (prompts: layout, reminders, equipment) How long are changes going to take? Are there systems for maintaining long term change?

Adapted from: Michie *et al* 2005 Making psychological theory useful for implementing evidence based practice: a consensus approach. *Qual Saf Health Care* 14: 26 – 33 [35]

## Appendix 7: Deviation from protocol

Aspect	Rationale
GP focus groups	Logistical challenges were experienced attempting to arrange group interviews for GPs. Resultantly, it was determined that individual interviews with GPs would provide good information for this research.
Number of GPs interview	Due to time constraints, it was decided that the two focus groups would be replaced with six individual interviews. This recognizes the additional workload impact on the researcher.
Number of patients interviewed	There were insufficient patients interested in this research to meet the 10 patients proposed originally. Attempts to recruit patients continued during the evaluation period, however only 4 patients agreed to participate. As each interviews with patients generated significant amounts of data, this was felt to be suitable for analysis purposes.