BMJ Open

Care home services at the vanguard: a qualitative study exploring stakeholder views on the development and evaluation of novel, integrated approaches to enhancing healthcare in care homes

Rachel Stocker,1 Claire Bamford,1 Katie Brittain,2 Rachel Duncan,1 Suzanne Moffatt,1 Louise Robinson,1 Barbara Hanratty1

ABSTRACT

Objectives To explore stakeholders’ understanding of novel integrated approaches to enhancing care in care homes (a care home ‘vanguard’) and identify priorities for evaluation.

Design A qualitative study, using semistructured interviews with commissioners and service providers to/within care homes, and third sector organisations with thematic analysis.

Setting A Clinical Commissioning Group (CCG) area in England.

Participants Thirty interviewees from care homes, the National Health Service (NHS; England) and local authority, third sector (10 care home managers, 5 general practitioners, 4 CCG employees, 4 local authority employees, 1 national (NHS England) vanguard lead, 2 specialist nurses, 2 geriatricians, 1 third sector and 1 health manager).

Results Four higher level themes emerged from the data: understanding of proposed changes, communication, evaluation of outcome measures of success, and trust and complexity. The vision for the new programme was shared by stakeholders, with importance attached to equitable access to high-quality care. Support for the programme was described as being ‘the right thing to do’, inferring a moral imperative. However, the practical implications of key aspects, such as integrated working, were not clearly understood and the programme was perceived by some as being imposed, top down, from the health service. Barriers and facilitators to change were identified across themes of communication, outcomes, trust and complexity. Importance was attached to the measurement of intangible aspects of success, such as collaboration. Interviewees understood that outcome-based commissioning was one element of the new programme, but discussion of their aspirations and practices revealed values and beliefs more compatible with a system based on trust.

Conclusions Innovation in service delivery requires organisations to adopt common priorities and share responsibility for success. The vanguard programme is working to ensure health and local authorities have this commitment, but engaging care homes that may feel isolated from the welfare system needs sustained dialogue over the longer term. Evaluation of the programme needs to measure what is important to stakeholders, and not focus too closely on resource consumption.

INTRODUCTION

The health and social care needs of residents in long-term care settings are increasing in complexity, as the number of older adults in the population grows.1 2 In the UK, bed numbers in care homes have remained stable in recent years, and the average age of residents is 85 years.2 Multiple morbidities are common; it is estimated that four out of five care home residents have a cognitive impairment while a similar proportion live with incontinence.3 4 Despite presenting some of the most challenging problems in primary care, care home residents are believed to have poorly coordinated services, worse management of long-term conditions and inequitable access to hospital care, compared with community dwelling older adults.5 6

Integrated working between healthcare and social care is advocated as an appropriate,
cost-effective way of improving quality of healthcare in care homes. However, integrated care has been defined and implemented in many different ways. The National Health Service (NHS) in England describe it as person-centred, coordinated and tailored to the needs and preferences of the individual and their family. To date, efforts to integrate care in a range of different countries and healthcare and social care systems have produced limited evidence of improved outcomes. A number of possible explanations have been proposed, including inadequate resources, the adoption of a meal rather than whole-system change and a failure to adequately involve service users and families.

The UK policy response to rising demands for better quality of care has included development of new, integrated ways of working. Investment in 50 different ‘vanguard’ programmes by NHS England in 2014 has focused on integrating primary and acute care, multispecialty community providers, urgent and emergency care, and acute care collaborations. Six sites were selected to enhance health in care homes, whereby residents are offered more integrated and coordinated healthcare by combining healthcare and social care services at a systemic level. Evaluation of any new intervention is essential to provide reliable evidence to inform commissioning choices. It is even more important in the case of the vanguard programme, as the new models aim to be replicable across England. Programmes that bring together healthcare and social care may be particularly challenging to evaluate. Multiple stakeholders may not agree on outcomes, information collection across settings can be difficult and appropriate sources of data may not be readily available. Many integrated care programmes aim to reduce resource use, and changes in unplanned admissions to hospital is a commonly measured outcome. Less tangible concepts, such as trust and collaboration between organisations, have also been proposed as indicators of success. There is a growing consensus around the need to scrutinise processes involved in any intervention, including feasibility and acceptability. Recent methodological developments, such as realist evaluation, have emphasised the importance of taking time to understand the complexities of the local context.

The proposed programme of change under investigation in this study consists of different work streams that encompass commissioning and service provision, care pathways, workforce and evaluation (box 1).

This paper reports on qualitative research aiming to inform the future evaluation of a new model of integrated care for care homes (care home vanguard) in England. At the time of the study, the vanguard programme was in the first year of development and had not officially started. In addition to identifying priorities and metrics for future evaluation, the vanguard team were developing and refining logic models to systematically consider the key components of the new care model and preparing for a full launch of the initiative. Study objectives were to (1) explore stakeholders’ understanding, perceptions and expectations of the new programme; how it will be implemented and how it might change care in the local context and (2) identify the priorities for the evaluation of the programme.

**SETTING**

The study took place in a single Local Authority administrative area and within a single Clinical Commissioning Group (CCG). This CCG is located within a post-industrial urban location characterised by large-scale, socioeconomic deprivation and poor health, being in the top fifth of most deprived local authorities in England with high rates of morbidity and premature mortality, and has suffered disproportionately due to austerity-driven public sector funding cuts.

**RECRUITMENT AND SAMPLING**

Semistructured interviews were conducted with 30 stakeholders in the local care home vanguard. Stakeholders were identified by the CCG from (1) the vanguard steering group, (2) local services that were involved in the commissioning or delivery of care for residents of long-term care and (3) organisations with an interest in the care and well-being of residents. The CCG acted as gatekeepers and sent introductory emails to potential participants, then provided the research team with relevant contact details. One of the researchers (RS) purposively sampled potential participants (n=61) using the list of contact details provided by the CCG and contacted them directly by email or telephone to invite participation, with a covering letter and participant information sheet. Non-responders (n=14) were reminded after 1 week. Twenty-eight respondents agreed to participate. Interviewees who were care home managers were asked to nominate colleagues from different homes to boost recruitment from this setting (snowball sampling); two further care home managers were recruited. No inclusion or exclusion criteria were employed. Participants’ roles in the care home vanguard are detailed in table 1.

**DATA COLLECTION**

Interviews were conducted in March–April 2016, by telephone or in person (at the participant’s workplace in a
private area), and lasted 30–60 min. A topic guide was developed, informed by published literature on implementing new models of integrated care for the elderly and the requirements of the research commissioners (see box 2). The topic guide was tested with members of the research team that included qualified doctors, allied health professionals and researchers with extensive experience of qualitative research. This aimed to ensure that the topic guide was practical, suitable for use in the time available and able to elicit the data required to answer the research questions. No further topics were added.

Written informed consent was obtained for all participants. All interviews were conducted by the same qualitative researcher (RS), audio recorded and transcribed. All transcripts were anonymised.

**DATA MANAGEMENT AND ANALYSIS**

A thematic analysis was conducted, using NVivo version 11 software to manage data. The interview transcripts were read and re-familiarised with the text. The interviewer coded every transcript line by line, and a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). Emergent themes were identified in a subset (10/30) of transcripts were coded by a second researcher (BH). The researcher (BH) read and re-read to familiarise ourselves with the text. 11 software to manage data. The interview transcripts were anonymised. Total 30

<table>
<thead>
<tr>
<th>Role</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care home manager</td>
<td>10</td>
</tr>
<tr>
<td>General practitioner</td>
<td>5</td>
</tr>
<tr>
<td>Community geriatrician</td>
<td>2</td>
</tr>
<tr>
<td>Older person’s specialist nurse</td>
<td>2</td>
</tr>
<tr>
<td>General practitioner transformation team</td>
<td>1</td>
</tr>
<tr>
<td>Third sector</td>
<td>1</td>
</tr>
<tr>
<td>Clinical Commissioning Group employee (leads for contracting, communications and engagement, vanguard manager, vanguard lead nurse)</td>
<td>4</td>
</tr>
<tr>
<td>Local authority (social worker, director of health and well-being, leads for vanguard and legal services)</td>
<td>4</td>
</tr>
<tr>
<td>NHS England vanguard team lead</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>30</strong></td>
</tr>
</tbody>
</table>

NHS, National Health Service.

FINDINGS

Participants were all stakeholders in the vanguard programme. Each had an interest in, or was engaged in, the commissioning or delivery of care for older people in care homes. Findings are presented across four higher level themes, which emerged from the data (1) understanding of the proposed changes, (2) communication, (3) outcomes and (4) trust and complexity. Verbatim quotations are presented to illustrate commonly expressed views or unusual or contrasting perspectives.

THE LOCAL CONTEXT

Interviewees highlighted aspects of the local infrastructure and services that provided a favourable basis for vanguard changes. The small geographical size, single local authority and single hospital (NHS Trust) were all expected to simplify relationships and communication. General practices in the area had a history of working well together. Relationships between hospital and community services were also good. Some felt that the generous provision of care home beds in this area meant that services did not have to strive hard to support patients in their own homes.

THEME 1: UNDERSTANDING OF THE PROPOSED CHANGES

A shared vision

A majority of the interviewees shared a vision of improved care and quality of life for older people in the vanguard area. The CCG had aspirations for equitable access to care—‘the right care, delivered by the right person at the right time’ and ‘one bed, one outcome’. Others shared these sentiments. Support for the vanguard was described by more than one interviewee, as being ‘the right thing to do’, inferring a moral imperative to the work.

The person is at the centre of it and if they need a wheelchair or a dietician, then they should get it. Not about who pays, what the financial consequences are. (Care home manager (8))

Interviewees were frank in their admissions of how little they understood about the vanguard programme, and how the vision would be achieved. This was attributed by some to the CCG’s desire to involve a wide range of stakeholders in service design and development, and the resulting inertia in getting started. Others blamed a lack of clarity from NHS England, which filtered down into local vanguards. This uncertainty limited external discussions about the programme.

The majority of care home managers were familiar with the headline proposals, even if they had little idea of how
the vanguard would influence their work. Staff turnover was a common issue; some care homes had new managers in post, which meant that initiatives (including vanguard) were not seized on. Care home managers talked about the pressing issues that they faced daily, particularly staffing and liaising with care providers from different sectors. This had consequences for their ability to fully engage with the vanguard.

**A top-down health programme?**

Strategic involvement of local and national bodies was highlighted as a major strength of the vanguard. However, engagement of a broad constituency also raised questions about differing organisational agendas and the threats that this may pose. A number of interviewees from outside the NHS expressed a perception that the vanguard was a health-dominated programme, imposed from above.

It feels like it might be being imposed, as opposed to it coming out of the experience of people working in care homes. (Third sector (1))

This feeling of imposition was explained in terms of historic links between care homes and general practitioners (GPs), and the fact that the vanguard is building on existing work rather than starting from scratch. There were concerns that a focus on health budgets and failure to align agendas would represent a missed opportunity to capitalise on an opportunity for radical change.

Vanguard in [Town 1] could be seen to be the catalyst for this real localised joined up working. But this is all just about health budgets. And it is all just about health driven issues. And I think that is the massive missing agenda. Because if you could get the Local Authority and Health to work on this, then they could be seen as an exemplar throughout the country. (Local authority (3))

The perceived imposition of the vanguard was discussed in relation to changes to commissioning and contracting, and how these would be resisted by care homes if they were not fully engaged.

**THEME 2: COMMUNICATION**

Communication was one of the most frequently mentioned influences on the success of the vanguard. Interviewees were concerned with the way in which information was communicated, as well as the content. Most talked of information sharing relating to the vanguard changes, but a significant minority also aired their views on patient or resident-related communication between health services and care homes, and different parts of the health service.

**A shared language**

The absence of a shared language among vanguard stakeholders was noted by a number of interviewees. Discussion in meetings and the vanguard documentation was described as jargon filled and potentially inaccessible to people from care homes and the third sector in particular. Some felt this limited their ability to engage in discussion and participate in the development of the vanguard.

The language that’s being used in some of the work planning, I think is extremely inaccessible. I don’t think people understand. […] It’s got a very clinical CCG kind of look to it. […] I just find it difficult when people jargon things up […] because it feels like it’s done and dusted, which it shouldn’t be. (Third sector (1))

The vanguard programme was acknowledged to be in development, so expectations of progress were modest. However, for some, their own lack of clarity as to the expected outcomes made communication about the vanguard difficult, within their own organisations.

**Information sharing**

Prompt and widespread diffusion of information about the vanguard was felt to be an important way of ensuring that care homes and others were engaged with the process. Information sharing was identified as a practical aspect of communication that could present a significant barrier. Many spoke of being unable to access electronic care records from other care settings. This created delays in obtaining information and duplication of effort for many healthcare professionals.

I think there needs to be better sharing of information. Around the access to our GP records. For people being able to look in, to know what I’ve done, or what I’ve said, so that there’s no duplication of information. (GP (2))

Nurses and care home managers reported delays in receiving records, and administrative barriers to records moving with patients. A number of participants also made a connection between transfer of information and patient or resident safety.

**THEME 3: EVALUATION OF OUTCOME MEASURES OF SUCCESS**

Interviewees proposed a range of measures to evaluate the vanguard intervention, reflecting concerns with structural aspects of the new model of care, the process of implementation and selected outcomes. Possible evaluation measures emerged across the interviews, at different organisational levels (individual, service, organisation and whole system) and perspectives (residents, staff and families). Where quantitative measures were proposed, someone, often the same interviewee, often suggested a complementary qualitative measure to understand or contextualise the information. Table 2 illustrates how some of the proposed measures fit together.

In addition to measures that the interviewees expected to be part of any evaluation, such as the number of hospital admissions, issues such as collaboration and trust between stakeholders were suggested as critical to
the development of the vanguard programme. Several interviewees emphasised the need to measure what was important, not what was easy to record.

If we could measure collaboration, I think it would be hugely beneficial, because I think that not only evaluates how the programme’s developing, but potentially collaboration is the solution to improving care and quality for patients, and value in the system. (GP (5))

Many mentioned the importance of person-centred outcomes, with an older population living happier and healthier lives as a measure of success. Goals defined by care home residents, their families and carers were considered to be a priority. None of the interviewees offered a clear definition of person centred, or reflected on how system and organisational outcomes might relate to changes for individuals. Concerns were expressed about the practical difficulties of capturing information from care homes and residents, including residents without capacity and the difficulty of interpreting information provided by proxies, such as family members, as they may not reflect the resident’s experiences.

### THEME 4: TRUST AND COMPLEXITY

Interviewees expressed a desire to see the vanguard programme bring different parts of the care community together, with a common purpose. The talk of shared vision and changes to hearts and minds, points to the expressed desire for trusting, collaborative relationships. The current reality for care homes appeared to be some way from this goal. Relationships between care homes and both health and local authorities were discussed in terms of mistrust and misunderstanding. This came from two key sources: the relationships that had developed over years of funding negotiations with the local authority, and the care homes’ experiences of regular interactions with the health service.

### Relationships with external services

Some care home managers felt that colleagues in the health sector did not respect their judgement and that care home staff were not trusted to provide a reliable report on a resident’s symptoms or healthcare needs. This was a particular concern with hospitals and the out of hours service. Relationships with GPs were generally reported in positive terms, but one care home manager described how GPs may not always appreciate the limits of the care home’s expertise in health matters.

We’ve had odd times where the GPs are like, “You don’t need to bother me with this. There’s nothing really wrong with them,” and you’re like, “Well, I know you know that, but we didn’t know that.” (Care home manager (5))

Much of the dissatisfaction expressed by care homes concerned the processes involved in the care system, predominantly the NHS. The absence of an individual to take responsibility or coordinate a resident’s care journey through external services was a concern.

The vanguard programme was seen as having the potential to address some of these concerns, improving care processes and efficiency of care pathways and enhancing trust between the sectors. Scrutiny of discharge transitions was presented as an example of how the vanguard might be able to effect change.

I think the process of discharge from the hospital could be measured better. Has there been an assessment done? Is the person being discharged with their medication, a discharge letter or any follow-up referrals? (Care home manager (7))

For the care home managers, funding issues were a negative influence on relationships between the local authority and care homes, and a source of mistrust. Care home managers expressed feelings of exasperation at what they perceived to be the local authority’s failure to

### Table 2: Matrix of evaluation measures: selected examples proposed by interviewees in the local Care Home Vanguard study

<table>
<thead>
<tr>
<th>Structure</th>
<th>Process</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>How many people are involved with</td>
<td>Quality of staff resident</td>
</tr>
<tr>
<td></td>
<td>resident (relational continuity)?</td>
<td>interaction How do the care</td>
</tr>
<tr>
<td></td>
<td>Medication reviews completed</td>
<td>home staff feel about the support</td>
</tr>
<tr>
<td></td>
<td>Does the resident have a care</td>
<td>they get from NHS relating to</td>
</tr>
<tr>
<td></td>
<td>plan in place?</td>
<td>medication?</td>
</tr>
<tr>
<td>Service</td>
<td>The role of skills development</td>
<td>Falls</td>
</tr>
<tr>
<td></td>
<td>in staff retention</td>
<td>Pressure sores</td>
</tr>
<tr>
<td></td>
<td>How many safeguarding alerts in</td>
<td>Nutrition</td>
</tr>
<tr>
<td></td>
<td>a care home?</td>
<td>Hydration</td>
</tr>
<tr>
<td>System</td>
<td>Delayed discharges</td>
<td>Resident well-being</td>
</tr>
<tr>
<td></td>
<td>Discharge processes</td>
<td>Death in preferred place of care</td>
</tr>
</tbody>
</table>

BMI, body mass index; NHS, National Health Service.
appreciate the pressures that they faced. Unfavourable comparisons were made with the funding agreements reached in neighbouring areas.

**Complexity**

The vanguard was portrayed as far-reaching, involving changes to an already complicated system of healthcare and social care. Concerns were expressed about the unintended consequences of integration between NHS and social care services.

My concern about [vanguard] is the NHS is a big monster at the moment that nobody controls. If you then amalgamated it with social services, it becomes a bigger monster that nobody can control. (Care home manager (3))

These concerns continued into the evaluation of large-scale changes, particularly attributing changes in different parts of the care pathway to patient outcomes. Some were concerned that they may be judged on outcomes over which they had little control. Measuring whole system outcomes was difficult and risked encouraging perverse incentives. Interviewees identified a need to ensure that changes in the care pathway were linked, in order to contribute to improvements for residents.

It’s separate components, provided by separate providers, under separate contracts. That can do two injurious things, one of which is a fragmented experience of care, but the other, and perhaps more important thing, is that it can create perverse incentives in the delivery of care. (Local authority (4))

Navigating complex systems was a source of frustration for clinical staff, who felt that longstanding processes and systems were bureaucratic and unwieldy. Vanguard was perceived as an opportunity to resolve some of these problems and improve clinicians’ ability to provide good patient care.

What I really hope [vanguard] will do, actually, is to get round some of the bureaucracy that we’re currently dealing with. That vanguard will have the weight to make changes. (GP (2))

**DISCUSSION**

**Summary of findings**

This study identified a consensus across a broad constituency that the ways in which services are provided for care home residents needed to change, and a shared belief in the benefits of closer working between healthcare and social care. The vision of the vanguard programme was supported overall, but the programme was perceived by some as being imposed, top down, from the health service. Some aspects, such as outcomes-based commissioning were not well understood, even by staff closely linked to the work. Barriers and facilitators to change were identified around communication, outcomes, trust and complexity. Great importance was attached to the measurement of intangible but important aspects of success, such as the level of collaboration.

A number of barriers to implementing a better system were identified, and most were regarded as challenging to overcome. Engaging people in a shared venture, when they are drawn from diverse professional backgrounds and employed by organisations with differing priorities, is not straightforward. Participants shared an interest in improving the well-being of older people in care homes, but the daily pressures of their work limited their involvement in new initiatives. Some of the anticipated problems, such as information sharing, had potential practical solutions. Others were more abstract. Many respondents talked of the need to promote collaboration and ensure shared values, but there were few ideas of how to achieve this in practice.

Understanding how a new model of care is going to influence outcomes for care home residents is likely to increase support for change. In this study, the vanguard initiative was seen as an opportunity to throw off some long established but unhelpful ways of working. Getting key players talking was one of the ways it was expected to effect change, along with breaking down barriers to shared information and records, reducing bureaucracy and promoting the role of the care home in the wider system. This study identified the concerns of care home managers, including a perception that they are outsiders in the process of service development. We interviewed one-third of care home managers in the vanguard area and found great diversity in the level of awareness and understanding of the vanguard. This suggests a need to devote resources to developing relationships, as involvement of the care home sector will clearly be essential to the long-term success of any changes. A programme evaluation that is meaningful to different stakeholders may be another way of fostering engagement. In this case, evaluation priorities focused on person-centred care. There was broad support for having a matrix of qualitative and quantitative outcome measures at different organisational levels, shared across different settings. This is in line with NHS England’s proposed approach to local vanguard evaluation, which combined understanding what works, in what context, with agreed metrics. Meeting resident and family expectations is an implicit goal for most services, and this was supported as a programme outcome.

**Strengths and limitations**

Our data were collected from a broad range of stakeholders, recruited from different settings. We cannot exclude the possibility that our close working with the CCG influenced the interviewees’ decision to participate or their willingness to share views and experiences. However, the critical content of the interviews suggests that this was not a major concern. The timing of our study, before the vanguard started, also presented challenges. It was inevitable that participants may not fully understand the scope or potential of the initiative. Recruitment of
stakeholders working in or with the care home sector, and briefing them on the vanguard before interviews took place, allowed us to collect useful data for analysis.

Comparison with other work
Previous evaluations of integrated care have identified issues that are key to ensuring success, including effective leadership, clear communication and a willingness to collaborate and engage with colleagues. 14 18 Findings from the organisational relations literature 20 24 highlight the importance of trust, appreciating complexity and understanding roles and responsibilities at all levels throughout the involved organisations. Our research reinforces the significance of this previous work for relation to future vanguard evaluations. Messages from the national team were reported to sometimes lack clarity and consistency, which adversely affected local understanding of the vanguard requirements. This echoes the findings of a recent review of integrated programmes that linked poor understanding of outcomes with limited insight into how the programme will effect change. 18 It is also consistent with previous work that stressed the importance of defining outcomes that matter to the service users and their families. 14 18

CONCLUSIONS
Innovation in service delivery for care homes requires some alignment of organisational agendas across health-care and social care. This study has emphasised how much effort this requires, even in a geographical area where local authority and health organisations already work together. The benefits of engaging the care home sector in change that they want and support are obvious, but the varied nature of the sector, current pressures and historical isolation from the NHS, make this a challenge. Evaluation of new programmes need to capture what is important to people receiving and providing care and not to simply provide evidence of reduction in resource consumption for the funders. The less tangible benefits, such as trust and collaboration should not be overlooked, even if difficult to measure.

Collaborators
Caroline Kavanagh, Shona Haining and Daniel Cowie.

Contributors
BH and RS designed the study with CB, KB, RD, SM and LR. RS conducted interviews. RS and BH analysed data. RS and BH drafted the article. CB, KB, RD, SM and LR performed critical revision of the article for important intellectual content. RS is guarantor of the article. All authors approved the final version to be published.

Funding
This work was supported by Newcastle Gateshead Clinical Commissioning Group.

Competing interests
None declared.

Patient consent
Detail has been removed from this case description/these case descriptions to ensure anonymity. The editors and reviewers have seen the detailed information available and are satisfied that the information backs up the case the authors are making.

Ethics approval
Newcastle University Faculty of Medical Sciences Research Ethics Committee.

Provenance and peer review
Not commissioned; externally peer reviewed.

Data sharing statement
No additional data are available.

Open Access
This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) licence, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/
© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2018. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

REFERENCES