Evaluation of a Trust-wide Nurse-led Advice Line for Service Users with Rheumatological Conditions

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Duration: March 2012 – December 2016

Keywords: rheumatology, evaluation, telephone advice line, nurse-led service

Project summary

The rheumatology advice line has been an integral part of the Clinical Nurse Specialist (CNS) role within the East Kent Hospitals University NHS Foundation Trust for 20 years. To date, there has been no formal evaluation of the effectiveness of the advice line service. Anecdotally there is evidence that service users appreciate the service. This project therefore aimed to evaluate the experiences of the nurse-led advice line from the perspectives of service users and other stakeholders; and consequently to identify areas for action to improve the service.

Four stakeholder events were held (three for service users and family members and one for professional stakeholders) during which three methods: a cognitive mapping tool; claims, concerns and issues; and a miracle question were used to explore participants’ experiences of the service provided by the nurse-led advice line. Data was analysed separately for each method and each event using an inductive thematic analysis. A second level analysis was then undertaken across all stakeholder groups to generate emergent themes.

Overall the feedback was positive and showed that the service was successful and valued. The access and promptness of response was recognised as a positive attribute. However, there was a feeling that the advice line was not advertised sufficiently. Service users also expressed a desire for more information, education and support in the form of a group setting. The key messages and headlines from the evaluation have been noted and an improved advice line service is being developed around them. In a climate when finances often dictate care, the project has highlighted the need to capture nurse-led activity in a more comprehensive way, linking this to efficiencies such as saved attendances at A&E or GP appointments.

This project was supported by the FoNS Practice Based Development and Research Programme in partnership with the General Nursing Council for England and Wales Trust.
1. Introduction and background

The purpose of this report is to share the findings of the first phase of a two phase project, supported by the Foundation of Nursing Studies (FoNS) Practice Based Development and Research Programme in partnership with the General Nursing Council for England and Wales Trust. The first phase has focused on an independent evaluation of the experiences of the nurse-led advice line from the perspectives of service users and other stakeholders. Phase two will involve the nurse-led team addressing identified areas for action to improve the service through a number of action cycles.

1.1. The nurse-led advice line

The rheumatology advice line has been an integral part of the Clinical Nurse Specialist (CNS) role within the Trust for 20 years. To date, there has been no formal evaluation of the effectiveness of the advice line service. Anecdotally there is evidence that service users appreciate the service.

Because of the complexity of drug regimens used to manage rheumatology, access to expert advice is crucial to maintain patient safety. Rheumatological conditions are subject to a huge variation in symptoms, it is therefore vital that service users are able to obtain advice and strategies to self-manage their condition appropriately.

Service users are provided with three methods of contacting the rheumatology team: telephone, text and email. The advice line service is available Monday to Friday during normal working hours. There is no cover for weekends, bank holidays or evenings.

2. The evaluation strategy

The aim of the evaluation was to identify how the nurse-led advice line was experienced by service users and professional stakeholders as well as identifying any areas for development. The evaluation questions were:

- What is the experience of service users and stakeholders of the nurse-led advice line?
- What areas are experienced positively by stakeholders?
- What areas need to be considered for further development by stakeholders?

The methods used to answer these evaluation questions are identified in Table 1.
### Table 1: Evaluation methods

<table>
<thead>
<tr>
<th>Evaluation question</th>
<th>Method</th>
<th>Data collection</th>
</tr>
</thead>
</table>
| What is the experience of service users and stakeholders of the nurse-led advice line? | 1. Collective claims, concerns and issues (Guba and Lincoln 1989) at stakeholder meetings on four sites  
2. Individual cognitive mapping tool to assess specific experiences and provide qualifying statements | Four stakeholder meetings:  
- Service Users:  
  1. Margate  
  2. Canterbury  
  3. Ashford  
- Stakeholders (managers, clinicians, commissioners)  
  4. Deal |
| What areas are experienced positively by stakeholders?                                | 3. Use of the miracle question from positive psychology                 | Used with all four stakeholder groups                                             |
| What areas need to be considered for further development by stakeholders?            | Analysis of the data arising from the above tools and other data volunteered One letter was provided independently of the stakeholder sessions | Data arising from the above has been analysed independently, then triangulated |

### 3. Methods

Consent to undertake the study was achieved through the NREC process 14/LO/1714. Participants were identified and recruited to the study by each CNS identifying stakeholders who had used the service in the previous three-month period. Potential recruits were provided with information about the study (see Appendix 1) and invited to attend a stakeholder event. A consent form was completed by participants (see Appendix 2).

The stakeholder events for service users all took place at venues independent to the hospital sites in Margate (Queen Elizabeth the Queen Mother Hospital), Canterbury (Kent and Canterbury Hospital) and Ashford (William Harvey Hospital). Both service users and carers/family members were welcomed and provided with tea and coffee. The stakeholder event for managers, clinicians and commissioners took place prior to and after a meeting at Deal Surgery.

Each stakeholder event commenced with an explanation about the study, reiterated informed consent principles and clarified that feedback provided would be anonymous, not linked to any one individual but would be collectively analysed for each event and used within the report anonymously. There was much interest in receiving the final report summary from all participants.

The process for each stakeholder event progressed similarly in the following order:
- Time to complete the individual cognitive mapping tool to assess specific experiences and provide qualifying statements (see Appendix 3)
- Group claims, concerns and issues identified on a flipchart (Box 1)
- Miracle question answered on an individual post-it (Box 2)

Box 1: Claims, concerns and issues (Guba and Lincoln, 1989)

What claims (positive statements) would you like to make about the nurse-led advice line?

What concerns do you have about the nurse-led advice line?

What issues (questions that any reasonable person would be asking) do you have about the nurse-led advice line?

Box 2. The miracle question (Pichot and Dolan, 2003)

The miracle question is a method of questioning that derives from solution focused therapy and psychology and can be used to invite a client to envision and describe in detail how the future will be different.

The miracle question asked was:
‘If you woke up tomorrow and a miracle had happened in the night and you had the most perfect nurse-led advice service for you, what would it look like?’

The numbers of participants attending each event are identified in Table 2.

Table 2: Participants attending each stakeholder event

<table>
<thead>
<tr>
<th>Stakeholder Venue</th>
<th>Number attending</th>
</tr>
</thead>
<tbody>
<tr>
<td>Margate</td>
<td>9</td>
</tr>
<tr>
<td>Canterbury</td>
<td>7</td>
</tr>
<tr>
<td>Ashford</td>
<td>14</td>
</tr>
<tr>
<td>Deal</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total Participants</strong></td>
<td><strong>34</strong></td>
</tr>
</tbody>
</table>

4. Analysis

Data was analysed separately for each method and each venue using an inductive thematic analysis. A second level analysis was then undertaken across all stakeholder groups to generate the insights into the three research questions. The emerging themes are detailed in the Appendices:
• Cognitive mapping - Appendix 3
• Claims, concerns and issues (CCIs) - Appendix 4
• Miracle question - Appendix 5

5. Feedback on the service

5.1 Areas well addressed
The feedback across the sites was positive and showed that the service was successful and valued. Comments about it being a ‘life line’ were repeated. There was a general feeling that knowing the person they were communicating with gave a sense of confidence that they were really being listened to. The access and promptness of response was recognised as a positive attribute.

5.2 Areas requiring action
There was a feeling that the advice line was not advertised sufficiently. Some service users believed that they were using the CNS personal number. It was felt by some service users that the voice mail message was too long.

5.3 Other things to think about
Service users expressed a desire for more information, education and support in the form of a group setting. The option of a home visit when housebound was mentioned.

6. Actions

Through a series of CNS meetings, some facilitated by Kim Manley (Associate Director Transformational Research and Practice Development, EKHUFT) using a CCI approach, a series of actions were developed (see Appendix 6).

The key messages and headlines from the evaluation have been noted and an improved advice line service developed around them. Formal education sessions have now been developed in two areas of the Trust.

7. Conclusion and recommendations

The rheumatology advice line is an effective method of providing easy access to all stakeholders. The quality of advice provided is of a good standard and its function reassuring to service users. The pressures on the NHS including difficulty getting GP appointments make services such as this essential in keeping service users safe and well. Currently there is no financial benefit to the Trust to delivering this type of service. In a climate when finances often dictate care we may need to capture the activity in a more comprehensive way, linking this to
efficiencies such as saved attendances at A&E or GP appointments. With funding it is possible that the service could be extended to cover out of hours working.

References


Appendix 1

PARTICIPANT INFORMATION SHEET FOR STAKEHOLDERS IN THE RHEUMATOLOGY ADVICE LINE

Study title:  Evaluating and Improving a Nurse-Led Rheumatology Advice Line

We would like you to consider taking part in a research study that will involve attending a group discussion in a venue local to you (see dates and venues at end of document). Before you decide you need to understand why the research is being done and what it would involve. Please take the time to read this information carefully and speak to others about the study if this would help.

What is the study about?
The aim of this study is to both evaluate and further improve the nurse-led advisory service to meet the information and support needs of patients with rheumatologic conditions across East Kent.

Why have I been asked to participate?
Any person who has either used the rheumatology advice line over a period of three months, or is a stakeholder (e.g. a manager or team member) in the service, can take part in the study.

What will the study involve?
The study involves attending a group discussion meeting lasting approximately one hour. This meeting will be led by an independent researcher who is not involved in the rheumatology advice service. At the beginning of the meeting the study will be explained and opportunities provided to answer questions. The focus of the discussion will be on your experience of the nurse-led advice line. You will be asked to consider what positive aspects of the service you have experienced as well as providing feedback on concerns and issues you may have. In addition, you will be asked for ideas and suggestions about how the service can be further improved to meet user needs.

The common themes arising from the discussion will be agreed at the end of the meeting and used together with feedback from all discussion sessions to inform an action plan for the nurse-led rheumatology team to take forward.

Are there any benefits for me to take part in the study?
Advice line users and stakeholders will have an opportunity to comment on the service they have received or experienced and we hope that the results will influence ongoing improvements within rheumatology services and inform further research.

Do I have to take part?
No - taking part in the activities associated with this study is entirely voluntary. It is up to you to decide. If you choose not to take part this will be respected and will not affect your care in any way. If you do decide to take part you will be asked to sign a consent form before being involved in any discussions.
**Will my information be kept confidential?**
If you agree to take part in this study, every effort will be made to maintain your confidentiality. Your name will not be disclosed and no personal information will be traced back to you. All information will be handled, and stored in accordance with the requirements of the Data Protection Act 1998.

It is important, however, to highlight that while information gained through discussion is anonymous there will always be the risk that your comments might be recognized. Should this occur, this will in no way effect any future care or treatment you receive. Also, in the interest of patient/client safety, if you report an area of poor or dangerous practice, the interviewer will need to speak with the senior manager from the area so that action can be taken to prevent similar situations occurring in the future.

You will however be given an opportunity to review quotations used in draft reports and request their exclusion.

**What will happen if I agree and then change my mind?**
You can change your mind at anytime and withdraw from the study and your decision will be respected and you can request that your comments within group data are not used.

**What if there is a problem?**
If you have concerns about any aspect of the study you can speak with the project supervisor, Dr Kim Manley or the project leader, Julia Witz (see contact details below), who will try to answer your questions. If you remain unhappy and wish to complain formally, you will be provided with relevant information by either the project supervisor/ project leader that will enable you to do so.

**What will happen to the results of the research study?**
The results of this study has the potential to provide robust information to the organisation for the purpose of evaluating and improving services for people with rheumatologic conditions. Once complete the study findings will be sent for publication in a professional and/or peer reviewed journal and/or may be presented at professional and lay conferences. Also a written summary of the key findings from the study will be available from the rheumatology department on request.

**Who is organising and funding the research?**
This study is being led jointly by the East Kent Hospitals University NHS Foundation Trust and the England Centre for Practice Development, Canterbury Christ Church University. Funding has been secured for the study from the Foundation of Nursing Studies – a charity based in London.

**Who has reviewed the study?**
The study has been reviewed by external experts for the Foundation of Nursing Studies and submitted to the UK Ethics Service, which ensures that all participating organizations have put in place assurances that the study will be conducted appropriately and within an ethical framework.
Reimbursement of travel expenses
We are willing to reimburse any reasonable travel expenses incurred. Further details will be made available upon request.

Further information and contact details
If you have any queries or would like further information on the study please feel free to contact the people below:

Professor Kim Manley
Associate Director of Transformational Research & Practice Development
East Kent Hospitals University NHS Foundation Trust
Kent & Canterbury Hospital
Ethelbert Road
Canterbury
Kent   CT1 3NG
Email:  kim.manley@nhs.net
Tel:  01227 766877 ext 73673 Mobile 07805 791606

Julia Witz
Lead Clinical Nurse Specialist Rheumatology
East Kent Hospitals University NHS Foundation Trust
William Harvey Hospital
Willesborough
Ashford
Kent
TN24 0LZ
Email: Julia.witz@nhs.net
Tel: 07831725140

Date and Venue
Monday 6th July at 6pm
The Conningbrook Hotel, Kennington, Ashford, TN24 8QR
Appendix 2

CONSENT FORM FOR USERS OF RHEUMATOLOGY ADVICE LINE SERVICE
& OTHER STAKEHOLDERS

Study title:  Evaluating and improving a nurse-led rheumatology advice line

1  I confirm that I have read and understood the information sheet dated <<insert date>> for the above study.  I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2  I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3  I understand that if poor or dangerous practice is reported that this will be discussed with the relevant senior manager by the researcher.

4  I consent to my comments being audio recorded as part of a discussion

4  I understand that the researcher will hold all information and data collected in a secure and confidential manner.

5  I understand no-one will be able to identify me through the reporting of this work.

6  I agree to take part in the study

Name of person: ______________________________________________(please print)

Signature of person: ______________________________   date: ____________

Name of researcher: __________________________________________ (please print)

Signature of researcher:___________________________________ date: ____________
Appendix 3

COGNITIVE MAPPING TOOL:

EVALUATION SUMMARY FOR ALL VENUES

1. Evaluation venue:
   Margate - **Total 10**
   Canterbury - **Total 5**
   Ashford - **Total 18**
   Deal - 2 **Total 2**
   Other (specify)
   N/A: 1

2. Please TICK the number of times you have accessed the nurse-led Advice line over the past 2 years
   - Once per year: **Total 4**
   - Twice per year: **Total 7**
   - More than three times per year: **Total 15**
   - Not used in my role: **Total 2**

3. Please TICK your position on the scale below in relation to the following statement. Then provide a justifying statement for your decision.

   **STATEMENT**
   I am satisfied with my experience of the nurse-led rheumatology advice line:
<table>
<thead>
<tr>
<th>Very Dissatisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>--</strong></td>
<td><strong>++</strong></td>
</tr>
<tr>
<td>0</td>
<td>24</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>-</strong></td>
<td><strong>1</strong></td>
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<td>1</td>
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<td><strong>+</strong></td>
<td><strong>11</strong></td>
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<td></td>
</tr>
<tr>
<td>11</td>
<td></td>
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</tbody>
</table>

- Concern have no 24hr care to manage flare-ups thought the number given was for repeat prescriptions
- Contacted on home number instead of mobile when abroad
- Told to stop Metrotrexate as liver function was 86 – Dr W definitely not
- Generally ok with advice line – does a good job
- Always got reply & advice – not always got answer from Dr but service good
- When in trouble good to talk to someone
- Always respond to emails within hours/same day. Always good at explaining over phone
- Happy with contact but didn’t realise was the advice line- would have used more
- Only because of individual nurse
- Provides link to nursing teams
- Sometimes a delay in responding
- Message on answer machine quite long
- Satisfied service is provided
- Would like further information about medication
- More convenient having service in same centre as GP
- Bringing my situation to attention of Dr
- Frees up time for GP
- Nurse-led service more personal & approachable
- Listen & do not brush off my concerns
- I would feel very alone/isolated without service without advice line
- Felt able to ring numerous times for advice – always helpful & patient
- Made a real difference always kind professional & knowledgeable
- Prompt response re: blood results/message
- Reassured could contact nurse to enable communication between all parties
- Telephone call saves OPD appointment
- Cost-effective
- Couldn’t cope without my nurse who is wonderful
- Practical advice & moral support for me as a carer
- Always listens & tries to see you when in trouble
- Personal service always get the advice whether answerphone or not
- Nurse fantastic at all times
- Provides valuable advice & contact for service users
- Provides excellent shared care which I find is supportive
- Helpful/satisfied - system works well
- A lifeline to me
- Immediate access re; flare-ups
## Appendix 4: Evaluation of Rheumatology Advice Line: Analysis of Claims, Concerns and Issues

**Venue:** Margate, Canterbury, Ashford, Deal

### CCIs Analysis

<table>
<thead>
<tr>
<th>THEMES</th>
<th>CLAIMS Responses</th>
</tr>
</thead>
</table>
| Accessible, quick access to response/referral | • Can get hold of them (timely)  
• Quick way of getting referral access to appropriate service  
• Enables nursing and medical team to be responsive to patient need  
• Accessible – phone call is easier than travelling to hospital which could take all day  
• Get a quick response  
• Responsive for patients with flares and concerns which need to get sorted quickly to avoid further distress/deterioration  
• Always get an answer x 2  
• Anything that helps to make Clinicians more accessible for patients is a good idea  
• Instant response almost the same day  
• Needed emergency appointment – arranged very quickly within a week  
• Always know who to send to (refer) and who will be sympathetic  
• Prompt and emergency service  
• I text Catherine and she gets back to me  
• Communication hub – on the case  |
| Feel supported, provides time, enables confidence – would feel isolated without it | • Very grateful for service, would feel very isolated without it.  
• Supportive  
• Gives patients confidence  
• Support from nurse – blue badge/lower rate  
• Able to give you a bit of time.  
• Felt could talk to nurse v consultant physician  
• It remains my firm conviction as a carer of someone who has RA and who has had experience of using the Advice Line via phone line, text messaging and email at first hand that this is a service valued not only for its economic and practical usefulness but also for the moral support and wellbeing of both sufferers and their carers. INDEPENDENT CORRESPONDENCE  |
| A life line – someone to phone! | • It’s my lifeline!  
• Totally dependent on Julia – she is my lifeline  
• Having someone to phone when you don’t know which way to go  
• After birth of baby got my life back from Catherine (GP didn’t know what to do)  
• If Catherine ever leaves we will move to follow her.  |
| Personal and people friendly holistic care and expertise | • Personal and people friendly  
• Treat you as a whole person rather than someone with RA.  
• Combined holistic care and expertise provided is recognised  
• Always get the feeling they know who they are talking to even though they have a lot of patients  |
| Provides care closer to home, avoids OPD appointment, A&E admissions | • Brilliant idea – stops patient needing OPD appointments  
• Provide care closer to home  
• Regarding the service provided by the hospital RA team in general I think it is an open secret that at least one of the Ashford GP practices would like to offer something similar at the practice. On the face of it a very practical innovation. Patients could avoid the need to travel to the WHH for their consultation and the treatment/medication readily available INDEPENDENT CORRESPONDENCE  |
| | • I now tend to first ring Catherine – take extra steroid/medication regime. Apart from two occasions save me going to A & E.  |
- Normally self medicate in situations where flare up is bad (normally ambulance to A & E)

**Reassuring that can access advice and rely on this as patient and carer**
- Reassuring having a contact number and email address who you can contact if abroad/travelling – for advice in a flare up or a new prescription
- Rely on Catherine for advice if needed
- Checks on blood results and advises consultant and GP.
- Only healthcare professional can phone up and talk to.
- It remains my firm conviction as a carer of someone who has RA and who has had experience of using the Advice Line via phone line, text messaging and email at first hand that this is a service valued not only for its economic and practical usefulness but also for the moral support and wellbeing of both sufferers and their carers. INDEPENDENT CORRESPONENCE

**Quicker action through Nurse Team, anticipates problems – is the best team I have experienced across 5 hospitals**
- Talking to nurse gets action quicker, rather than waiting to see Dr/getting hold of Dr’s secretary.
- Nurse pushes consultant to act on your behalf
- Ran service for 6 months whilst without a consultant physician
- Clinic in GP practice – ran
- Can create a team around you
- Anticipates problems – her finger on K linked to RA
- Experienced 5 other hospitals – this is the best
- The team is good
- It’s very necessary as consultant appointments a long way apart.

**More positive outlook for disease**
- Through Catherine I have more positive outlook for my disease
- Managing and increased caseload as most living longer

**Well informed, knows me and acts as an advocate**
- Nurse knowledge is better than consultants – whereas having to start afresh with consultant each time.
- Well informed
- Someone who you know and who knows you and your history and medications
- Julia has situational awareness of individuals – acts a advocate to patient
- Knowing her patients and listening
- Being our advocate e.g. blue badges
- Very knowledgeable about condition. GP doesn’t know the answers to many questions.
- Are specialists

**Improves outcomes**
- Improved outcomes not admitted. Act as advocate to GP

**Saves money and resources**
- Saving a lot of money and massive resources
- Can have spaced out appointment – more cost effective
- It remains my firm conviction as a carer of someone who has RA and who has had experience of using the Advice Line via phone line, text messaging and email at first hand that this is a service valued not only for its economic and practical usefulness but also for the moral support and wellbeing of both sufferers and their carers. INDEPENDENT CORRESPONSE

<table>
<thead>
<tr>
<th>THEMES</th>
<th>CONCERNS</th>
<th>ISSUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raising awareness of the role and purpose of the Nurse-led advice line</td>
<td>Many GPs not aware about it</td>
<td>What is the Nursing led advice line?</td>
</tr>
<tr>
<td></td>
<td>Service needs to be promoted</td>
<td>Are patients aware of the purpose of the advice line?</td>
</tr>
<tr>
<td></td>
<td>Didn’t know it was advice service</td>
<td>Perhaps could have a leaflet to describe what can give advice on?</td>
</tr>
<tr>
<td></td>
<td>Didn’t realise the expertise of advice team</td>
<td>How available is the service?</td>
</tr>
<tr>
<td></td>
<td>and that they would advise on different drugs, eg ?? for hospital – don’t publicise advice you can get.</td>
<td>When should you phone it?</td>
</tr>
<tr>
<td></td>
<td>Tend to manage for as long as possible</td>
<td></td>
</tr>
</tbody>
</table>
| 2-way communication between GP & Nurse-led service | • Feedback from nurse-led advice line to me (the GP)  
• Only Mon-Fri  
• Communication between nurses and my surgery e.g. blood tests.  
• Requested copy of letter from Dr to GP but not received  
• Book doesn’t get filled in consistently re medication (GPs) | • How can the communication be improved both ways? (Advice Line & GPs e.g. Blood tests)  
• Will they tell us to use GP?  
• Does the nurse/Dr have a record or number of times been unwell with immune system or other illness connected. |
| Influence of consultant nurse pilot on the advice line | • How will the Consultant nurse pilot influence the nurse-led advice line?  
• How should the nurse-led advice line influence the pilot? |
| Cover for sickness and holidays | • Cross cover arrangements for sickness  
• Therefore arranging holidays around delivery |
| Succession planning | • What is the succession plan  
• Why is more not being done to get newly trained clinicians and keep them  
• There may not be a planned overlap in succession plan  
• Developing other clinicians e.g. number of doctors  
• Management top heavy – not allow most to sideway train |
| Answer machine message is too long | • Answerphone message on the advice line is long before patient can leave a message |
| Blood tests communication | • Hospital required regular blood tests  
• Surgery doesn’t see blood test results therefore pressure on patient to have blood tests.  
• Copy of blood tests needs to be sent to GP from WHH.  
• Would be marvellous to have a text to say you are due for a blood test.  
• Don’t get a copy of blood results – haven’t had them since at Margate. VCN did this without fail. |
| More proactive contact with Nurse/Dr | • More contact proactively from nurse/Dr to prevent unnecessary hospital admission/quality of life  
• Lack of opportunity to catch up with the Dr. |
| Difficulty getting appointment with Dr | • Nurse requesting an appointment with Dr – appointment doesn’t materialise.  
• Getting an emergency appointment at times persistent flare up  
• OPD appointment with Dr if away for period of time/has to be new referral by own GP. |
| Information about medication and sequencing of | • Don’t have enough information about medication – feel a bit left/on your own  
• Drugs so new – not in GPs | • May be useful if nurse led team explain what you are taking and why, and links |
| Medications | with antibiotics and chicken pox (intervention)  
| • Do you have to be on one medication before next one tried? (If knew normal sequence and what to expect – would persevere)  
| • Do they have access to information leaflets about drugs/related areas  
| • I’m told with new treatment I will get better – 2 day – how do I know I am better?  
| • Concern when appointment moved from 4 – 6 months when on??  
| Flexibility around prescriptions if on holiday | • Prescription is four weekly from BUPA – problem arises when need extra 2/52 before holiday  
| Delays in seeing leads to more admissions | • Delay in seeing Catherine (December – March) when having a bad time/not coping – leads to delay in recovery or admitted to A&E.  
| • So if realised quicker may not have ended in A & E – now err on side of caution.  
| • Can’t walk to Ambulatory Care unit.  
| RA not seen as a disability | • RA not seen as disability  
| • Feel as I get older the consultants are not interested – told probably osteo and not RA but on one examines you to find out.  
| • Team didn’t listen to them and act to me when my issue was not RA (listened but didn’t act)  
| • Isn’t choice for treatment AT QEQM  
| Worried about phoning about stupid things | • Too worried about phoning about stupid things  
| Emotional support/support group | • Need for a support group sharing ideas/emotional support.  
| Fear about any future dilution of current highly trained and experienced team and lower level of expertise in RA by GPs | • From the comments of those attending the Focus Group meeting at the Conningbrook on Monday evening and who represent a small sample of the total cohort, it became clear that their wide ranging experience of the progression or otherwise of their respective diseases represents the need for a highly trained, extensively experienced and knowledgeable team devoted solely to the diagnosis, medication and treatment of this complex disease. Any attempt to “dilute” this can only be counterproductive and ultimately self defeating.  
| • My concern and that of others is mainly that of the level of expertise to be found there (in GP practice). It is well documented that | • Most don’t have the specialist knowledge (GPs)  
| • Tendency to under prescribe/over prescribe when inexperienced |
Diagnosis of RA and its related but distinct variants is invariably time consuming and complex. In some instances, it has taken patients years of frequent visits to their GP before they have even been referred to a Rheumatology clinic. Yet these same busy GP’s who are constantly dealing with the primary care of a whole range of patients with very different care needs consider themselves sufficiently knowledgeable to

- Itinerary – unaware not up to date as very specialist
- Requested change in one medication but not acted upon unlike husband’s experience in private sector
- If with seeing the GP (not specialist) seeing the consultant.
- Worried – GP practices RAN

| Need 24hr service/emergency slots | Line should be available 24 hours |
| Lack of info about pregnancy | Lack of information about pregnancy |
| Uncertainty/fear for the future | Funding may be removed from the service
- Lack of communication about intentions due to change over new consultants
- Is there a master plan to manage increased number of patients.
- ? extra clinics on less sites only allowed to respond to set number of patients, can see so frequently
- Not informed about plans for future |
| Is it possible to have emergency slots (face to face) available. |
| What are plans for the future? |
| Frequency of appointments – may be reduced |
| Will it (NAS) always be available? (fear about cuts due to election) |

| The Nurse-led advice line – is it cost effective/what are the alternatives | Is it cost effective? |
| How much does it cost? |
| What is the alternative to NRAS? |
| Is there an alternative? |
| Whether nurses work themselves into the floor/too hard! |

| Positive feedback less quantifiable | Positive feedback less quantifiable |

| Miscellaneous | Can’t understand what some doctors are saying who have come from abroad |
## Appendix 5: Miracle Questions Analysis

**Margate, Canterbury, Ashford, Deal**

<table>
<thead>
<tr>
<th>INDIVIDUAL RESPONSES</th>
<th>THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>• More specialist nurses with a 24 hours service</td>
<td>24 HR SERVICE 7/7 ‘Knowing the advice line is always there’</td>
</tr>
<tr>
<td>• Advice and guidance 7/7”</td>
<td></td>
</tr>
<tr>
<td>• “7 days a week. Responses to urgent calls (not everyday).</td>
<td></td>
</tr>
<tr>
<td>• Knowing the advice line is always there should I need advice and information</td>
<td></td>
</tr>
<tr>
<td>• “Manned at all times of the day/evening to capture all patients, ability to signpost/give advice and also to give feedback on where it can improve</td>
<td></td>
</tr>
<tr>
<td>• 24 hour help line</td>
<td></td>
</tr>
<tr>
<td>• To be able to talk to somebody who is aware of RA 24 hours a day – 7 days a week</td>
<td></td>
</tr>
<tr>
<td>• Advice Line: Available 7 days a week, manned by specialist rheumatology staff</td>
<td></td>
</tr>
<tr>
<td>• Possible local or free phone number</td>
<td></td>
</tr>
<tr>
<td>• To continue as is but to cover a wider area with the Helpline 24/7</td>
<td></td>
</tr>
<tr>
<td>• 24 hour rheumatoid trained helpline preferably Julia!</td>
<td></td>
</tr>
<tr>
<td>• To have access within a couple of hours to a nurse and the support/advice that I need. Which is basically what I already get!</td>
<td>Immediate access/fast track within a couple of Hrs – which I already have But also provide for Drs</td>
</tr>
<tr>
<td>• “Immediate access, ie within 30 mins – Fast track referral to relevant service.”</td>
<td></td>
</tr>
<tr>
<td>• Good if advice line is open for GP’s if they have patients they need assessed quickly</td>
<td></td>
</tr>
<tr>
<td>• Advice line: Have access to booking emergency slots at clinics</td>
<td></td>
</tr>
<tr>
<td>• The perfect advice line would provide support not just with medication but also with my individual needs in general</td>
<td>Proactive support &amp; contact not just medication but individual needs</td>
</tr>
<tr>
<td>• To contact me personally instead of me having to contact and feel a nuisance</td>
<td></td>
</tr>
<tr>
<td>• A service where they contact you and advise of new medication and services that would make your quality of life and pain management more complete.</td>
<td></td>
</tr>
<tr>
<td>• ‘proactive’ element i.e. nurse phoning unstable patients to see if management plan is working</td>
<td></td>
</tr>
<tr>
<td>• Listening when feeling low or anxious. To be listened to and not rushed. Regular contact both ways</td>
<td>More time so feel listened to</td>
</tr>
<tr>
<td>• To feel listened to and a bit of time</td>
<td></td>
</tr>
<tr>
<td>• Time</td>
<td></td>
</tr>
<tr>
<td>• time for counselling if necessary..</td>
<td></td>
</tr>
<tr>
<td>• A speciality nurse accessible, is a huge step forward, excellent</td>
<td>Already 100% successful – a huge step having a speciality nurse</td>
</tr>
<tr>
<td>• As an advice line it is 100% successful</td>
<td></td>
</tr>
<tr>
<td>• The personal aspect of Julia knowing us so well is not to be underestimated</td>
<td>Replicate service provided by Julia</td>
</tr>
<tr>
<td>• Julia</td>
<td></td>
</tr>
<tr>
<td>• Julia as she is now nobody could do more!</td>
<td></td>
</tr>
<tr>
<td>• Replicate the service provided by Julia Witz</td>
<td></td>
</tr>
<tr>
<td>• Julia’s knowledge/skills shared and cascaded across the county and advice line</td>
<td></td>
</tr>
<tr>
<td>• “Could robust use of the calls reduce face to face contacts?”</td>
<td>Reduce face to face contacts/clinical appointments</td>
</tr>
<tr>
<td>• Could be helpful to avoid unnecessary clinic appointments for stable patients</td>
<td>Support groups for patient &amp; carers</td>
</tr>
<tr>
<td>• “engagement with patient groups and carers support groups”</td>
<td></td>
</tr>
<tr>
<td>• Finding out what is available as support, drug options, local group</td>
<td></td>
</tr>
<tr>
<td>• consider distributing more info or flyers/posters to Surgeries to help promote this and make everyone aware of the Service</td>
<td>Promote service via flyers/posters to surgeries and more widely</td>
</tr>
<tr>
<td>• As well as the phone line, they could offer home visits,</td>
<td>Offer home visits</td>
</tr>
<tr>
<td>• ...could be a patient advocate within other departments, where patients has more than one condition...</td>
<td>Patient advocate for other depts where more than one condition</td>
</tr>
<tr>
<td>• I really don’t know, I thought you meant a miracle cure. The place where the appointments take place could be more cheerful. That’s being picky – I don’t recall any bad treatment. Very helpful concern to answer any questions.</td>
<td>Place where appointments take place could be more cheerful</td>
</tr>
<tr>
<td>• Work in partnership to help me give more information so I could help myself explain the plan to help my arthritis work with different doctors</td>
<td>Work in partnership – with Drs – so I can help myself</td>
</tr>
<tr>
<td>• The service would be as it is now but with the sense of security that it will always be available</td>
<td>Sense of security that the service will always be there</td>
</tr>
</tbody>
</table>
- Quality succession must be ensured.
- To feel confident that the quality of the current RA Nurse be supported and that they be supported which in turn supports the patients.
- It would often prompt ourselves and work together with other services available within the local community.
Appendix 6. Nurse-led Advice Line Actions

Key Messages and Headlines from the Evaluation

POSITIVES

- Already hugely successful and valued resource
- Benefits and impact recognised i.e. saving time for other health providers, preventing OPD appts. etc.
- Accessible, responsive
- Reassuring and would feel isolated without the service – it’s a lifeline. Good to talk to someone when in trouble
- Personal and people friendly – knows me and my medication – only health service I fell I can phone up and talk to
- Gets quicker action when talking to the nurse
- Informs me promptly of blood results
- Satisfied with service only because of individual nurse
- Service available in same centre as GP

PRIORITIES TO ADDRESS OR CONSIDER

- Concept (Advice line) – defined purpose and what it does which is promoted as a specific service for patients, carer and health care staff (GPs community staff etc). Many GPs not aware of it and need access to support and info too
  - What is the phone number/
  - Include expectations in terms of access time and responses
  - Information sheet/flyers for surgeries (and ? websites)
  - Agree contact numbers for contacting patient e.g. patient abroad need urgent advice but contact when to home number rather than mobile
- 24 HR 7/7 Service
- Better partnership working with GPs so I can help myself
  - Better communication between Advice line and GP – written/feedback
- Proactive support – ‘me as a person’ not just ‘me as my medication’
  - Linking with others re co-morbidities/ advocacy around this
- Positioning the consultant nurse service to this (whole systems approaches)
- Answerphone message – very long before patient can leave a message
  - Response times – consistency
- Text reminders for blood tests
- Medication changes requested but not acted up on – team listened to me but didn’t act
- Getting emergency appointments/ referral to seeing Consultant
- More information on medication for service users
- Feel not informed about plans for the future
OTHER THINGS TO THINK ABOUT

- Support groups for patients and carers/ counselling
- Home visits

<table>
<thead>
<tr>
<th>ACTIONS TO BE CONSIDERED</th>
<th>PLAN</th>
<th>WHO &amp; HOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need to promote the advice line and purpose more widely</td>
<td>Produce a standardised sheet (corporate logo) Use business card to better effect – statement on back Update website Signature manager</td>
<td>JS – to look at QE info sheet and adapt. Agree statement for card and update website – liaise with comms Email team with signature info</td>
</tr>
<tr>
<td>Consider 24/7 service to patients, carers, GPs Develop fast track service</td>
<td>Prospect of new service design may follow Deal pilot. 24 hour return of call already happening</td>
<td>JW to put update of service redesign in report Everyone to report end of month % of patients who had an attempt of contact made in 24 hours (message left if answer machine) – any volunteers?</td>
</tr>
<tr>
<td>To improve communication with GPs, to clarify roles, reduce mixed messages, process obtaining urgent appointments and managing blood results</td>
<td>Most of this covered by Deal pilot</td>
<td>JW to include the integrated working aspect of the pilot, changes to DMARD monitoring, facilitating urgent con appts by reducing routine work.</td>
</tr>
<tr>
<td>To consider role of support groups and/or other strategies for patients and carers to have more time to be listened to.</td>
<td>Formal evaluation of current groups.</td>
<td>JW to provide Deal group with a questionnaire to formally evaluate the monthly sessions. KW to provide a statement from the NRAS group/patient</td>
</tr>
<tr>
<td>Consider how to improve cover for sickness and annual leave across the service and maintain consistency in response times</td>
<td>Include information about this in the patient info sheet</td>
<td>JS to lead –Statement for nurses sent as part of this email</td>
</tr>
<tr>
<td>Implement systems to ensure most relevant numbers are stored. Reduce length of message</td>
<td>Numbers stored on patient centre which is secure. Some numbers saved on mobile phones.</td>
<td>Done already. Message will be consistent across the Trust but accept different areas have different needs.</td>
</tr>
<tr>
<td>Already a successful service, need to replicate and ensure quality for the future.</td>
<td>To continue to provide regular audits to measure ongoing satisfaction. Investigate more work done on the phone in the future, saving patients trips to hospital if</td>
<td>Annual small audit – 10 patients per con – any volunteers (small questionnaire) JW to discuss telephone consults as part of the Deal pilot</td>
</tr>
<tr>
<td>Consider more proactive support/home visits to patients and carers</td>
<td>appropriate.</td>
<td>JW to include as part of the wider community influenced by the pilot</td>
</tr>
<tr>
<td>Develop future direction with service users to address fear of the unknown, build in succession planning and the role and contribution of the CN in future service delivery</td>
<td>To focus on integrated working across the patient pathway</td>
<td>JW can use examples of positive changes to the patient pathway which include sharing the care of the patients in a more connected way, resulting in less dependency on secondary care.</td>
</tr>
<tr>
<td>Develop further information resources around medications, their sequencing in treatment and pregnancy</td>
<td>Link this information to a public website</td>
<td>JS &amp; HM (have included you Hazel) to work with comms to develop an improved website. Consultant input will be more inclusive but this is nurse led as part of this research</td>
</tr>
<tr>
<td>Explore interdisciplinary advocacy process with other departments where there are co-morbidities</td>
<td>Develop more integrated ways of working through shared knowledge and improved communication</td>
<td>JW to evidence as part of the Deal pilot. SurveyMonkey data/patient feedback/</td>
</tr>
<tr>
<td>Develop a process for greater flexibility in prescriptions linked to holiday absences</td>
<td>Add information on this to info sheet</td>
<td>JS to include</td>
</tr>
<tr>
<td>Develop greater insight into cost effectiveness of the service and the impact on admissions</td>
<td>Consider collecting data via Cassandra</td>
<td>KM to brief the team</td>
</tr>
<tr>
<td>Consider how local clinic environments can be improves</td>
<td>Feedback to the Estates department Ensure the rheumatology clinics run smoothly, to time and all information required for patients is present.</td>
<td>ALL</td>
</tr>
<tr>
<td>Consider implementing more creative approaches to gathering positive feedback on a more regular basis ie patient narratives, emotional touchpoints</td>
<td>Undertake an emotion touchpoint session with just one patient every few weeks – record and disseminate the information, establish themes to improve, celebrate. Record patient stories (anonymously) to celebrate good work and positive patient experiences – link with ACE (Achieving and Celebrating Excellence in care)</td>
<td>ALL</td>
</tr>
<tr>
<td>Work with local charities</td>
<td>Link with the support group section already documented</td>
<td>ALL</td>
</tr>
</tbody>
</table>