Developing a Quality of Life Score for Crohn’s Anal Fistula (CAF-QoL)
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St Mark’s Hospital

IBD Patient Involvement in Research Day
Friday 18th May 2018

#IBDPRD
Summary

We aim to develop a new patient-centred quality of life assessment scale with the help of people living in the community with Crohn’s-related perianal fistulas. We will call this the Crohn’s Anal Fistula Quality of Life scale (CAF-QoL). It will help healthcare professionals understand how a perianal fistula affects their patient and help them in their treatment decisions.

Demographics

<table>
<thead>
<tr>
<th>Summary</th>
<th></th>
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<tbody>
<tr>
<td>Respondents:</td>
<td>23</td>
</tr>
<tr>
<td>Male:</td>
<td>11</td>
</tr>
<tr>
<td>Female:</td>
<td>12</td>
</tr>
<tr>
<td>Crohn’s</td>
<td>23</td>
</tr>
<tr>
<td>UC</td>
<td>0</td>
</tr>
<tr>
<td>Median Age</td>
<td>43</td>
</tr>
<tr>
<td>Mean Age</td>
<td>41.1</td>
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</tbody>
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PPI themes and discussion

1. Reducing Drop-out rate

- Email reminder
- Calendar update
- Text message with a link to take you to the page

2. Maximising recruitment

- Patient panels for IBD - Patients want to hear from clinicians about how they can be helpful
- Get in touch with those who run the Facebook groups
- CCUK and other charities
- Most of those in the online community would be keen to learn and be involved in research
- Facebook sponsored posts can be used – good way to reach people
- Need to reduce the gap between doctors and patients
- Hashtags on Instagram and Twitter for those who choose not to join Facebook groups
- Tools can be used on social media to prominently promote research within groups
3. **Electronic surveys**

- Make both options available
- Issues are finding time for face-to-face or paper forms and online survey could be better
- Online would be easier and recruit a larger group of patients
- Research nurses could be helpful for patients who are not using the internet; perhaps an extra 5/10 mins while already attending clinic
- Currently done on Get Your Belly Out page by different researchers

**Other topics raised by group:**

a) **Will there be translations done?**
- Cultural issues as well which need to be thought of
- Challenging but important

b) **How to tackle hard to reach groups**
- Not on social media
- Not having access to IBD nurse
- Can you get surgeons to ask patients if they would like to be involved in trial?
- Recruit patients at your own hospital