

crohn's and  
colitis  
UK



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# IBD PATIENT PANELS

## GUIDE TO GOOD PRACTICE

# GUIDE TO GOOD PRACTICE - APPROACH

- Partnership: patients and professionals working together to bring about improvements. Modelling a relationship of collaboration and mutual respect - aim to have IBD Department representative at all meetings

# GUIDE TO GOOD PRACTICE - APPROACH

- Understand the different ways a Patient Panel can work to bring about improvements in IBD services:-
  - Internal improvements by sharing experiences; acting as a sounding board and by offering new ideas
  - Beyond the department by advocating for more resources for IBD Services to achieve improvements

# GUIDE TO GOOD PRACTICE - APPROACH

- Aim to achieve an understanding of the NHS and how it works

# GUIDE TO GOOD PRACTICE - APPROACH

- Inclusiveness:
  - try to represent the diversity of IBD Patients
  - look beyond the Panel's membership (surveys etc)
  - ongoing recruitment of new members (and where appropriate their carers) who also currently use the hospital's IBD service

# GUIDE TO GOOD PRACTICE - WORKING PRACTICES

- Patient Leadership; chaired by a member of the Panel and an opportunity to set its own agenda
- Members working and acting together - not independently

# GUIDE TO GOOD PRACTICE - WORKING PRACTICES

Be organised:-

- Regular Meetings – minimum of 4 times a year
- Agenda & notes of meetings
- Keep an up to date (e)mailing list/telephone numbers

# GUIDE TO GOOD PRACTICE - WORKING PRACTICES

**Planning:** work towards improving IBD Services in a structured way. Have clear aims and objectives. Patient Panels do need to have a focus - don't try and deal with too many issues at once. Achieve this by having a Work Plan – based on IBD Standards/Patient Journey. Review achievements against Work Plan - annually.

# GUIDE TO GOOD PRACTICE

## - Relationships and Links

- Relationship with Crohn's & Colitis UK – take advantage of national training and advice.
- Keep Crohn's & Colitis UK informed so that they can disseminate good practise and lessons can be learnt from Panels' experiences

# GUIDE TO GOOD PRACTICE

## - Relationships and Links

- Local relationships - keep local Crohn's & Colitis group informed and involved
- Be aware of allies and Patient Panel networks; other user groups in hospital, formal department within Trust, Trust management: Foundation Trust Membership: PALs: LINKs and CVS

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