Carolyn Wheatley
Empowering people on home artificial nutrition to take responsibility
HPN patient
Chair PINNT
BAPEN executive officer
How do we empower people to take responsibility?

Define what ‘empowerment’ and ‘responsibility’ means to them?

Resources: format, dissemination and accessibility

Accountability?

Do empowerment and responsibility = Quality of life?

PINNT: Home Artificial Nutrition:

- Enteral
- Parenteral
- Oral supplements

Support

- Patients, family, friends
  - helping each other

Education

- Showcasing life on HAN from the patients / carers perspective

Collaboration

- Work with professional bodies, manufacturers, policy makers, service providers...
Clinical Standards for Home Parenteral Nutrition in Scotland:

- **Clinical Standard 2**: Patient Information and education
- **Clinical Standard 8**: Follow up and monitoring

Quality Standards for Nutritional Support in Adults:

- **Quality statement 4**: Self-management of artificial nutrition support
- **Quality statement 5**: Review

☑️ Promise made to patients
☑️ Promises made to your patients
Quality and Clinical Standards are:

• Relevant to enable people to feel empowered and assume responsibility
• Relate to clinical care
• Concise

• Are patients aware of the Clinical and Quality Standards?
• Do the clinicians know about the promises made to their patients?

• PINNT frequently deal with the non delivery of these promises
BAPEN and PINNT are committed to improving the care of those receiving artificial nutrition support

In January 2020 we will surveying patients on home enteral feeding

Have they been given the support and ongoing care in order that they need to manage their tubes and feeding with confidence

The results of this survey will inform a 2020 workstream to ascertain if the NICE Quality Standards - Nutrition Support in Adults (2012) are being adhered to

We look forward to sharing the results - our plan...
BAPEN and PINNT promise to...

Ken Mastris
Prostate cancer survivor
European Cancer Patient Coalition

“You don’t always ask the right patients for their opinions”
• **Empowering** people to have their artificial nutrition in a time and place that meets their needs.

• Patients taking **responsibility** to provide information to #verify the essential medical equipment

• **Confidence** to be part of society thanks to their artificial nutrition
How should we empower people to take responsibility?

Define what ‘empowerment’ and ‘responsibility’ means to them?

Resources: format, dissemination and accessibility

Accountability?

Engage widely to develop the right resources for patients

Listen

Relevant, effective and deliverable

Policy makers must keep their promises

Do empowerment and responsibility = Quality of life?

TEAM TOGETHER EVERYONE ACHIEVES MORE
Supporting people on home artificial nutrition

Thank you