# British Porphyria Association Conference Cardiff 2017

Tricia Gardiner

Clinical Nurse Specialist

# Specialist Nurse Role

Clinical Practice

Education

Professional Development

Networking

Counselling

Collaborative working

Administration

# National Acute Porphyria Service Specifications

- Aim to reduce the risk of further attacks through education and safe treatment of any associated medical conditions. Send ‘porphyria pack’: porphyria information, emergency protocol, safe list, medi alert etc if unable to travel to Cardiff or out reach clinic.
- Following a new diagnosis arrange out reach appointment within 6 weeks or arrange teleconference with Dr Badminton.
- Regular telephone/e mail contact to patients in between appointments
- Written protocols to assist local teams e.g. Haem arginate guide, urine PBG guide etc.
- Offer psychological support to relieve distress and anxiety which can be a consequence of a new diagnosis
- Carry out patient satisfaction surveys to gain patients feedback to enable us to improve service.

# In Patient

- Provide appropriate support for clinical staff managing patients with a rare disease: offer guidance on management of an acute attack.
- Improve patients quality of care during their admission:

  Ensure emergency protocol is followed (ideally in Emergency Unit if we are  aware they have been admitted )

  Regular contact with ward nurses, to provide advice and support re: port a cath's, administering haem arginate (often for the first time ), care of venflon (risk of extravasation).

  Advice re pain management, involve pain team early.

# Outpatients

- Provide support to homecare nurses, haem arginate administration and port complications.
- If patients develop symptoms of an acute attack liaise with homecare team and possibly offer an extra dose of haem arginate at home (M - F) which can prevent admission to hospital, if the patient can manage other symptoms pain, nausea etc.
- Support nurses in day units administering prophylactic haem arginate to patients regularly.
- Organise 6 monthly appointments, blood tests and urine PBG levels for patients receiving prophylactic haem arginate .
- Make new patients aware of BPA web site, to enable patients to access support with other patients who have experienced acute attacks, also access fact sheets available on web site.
- Encourage patients to access
  www.wmic.wales.nhs.ukspecialist-services/drugs-in-porphyria/

- Out reach clinic: 8 a year
  Scotland twice a year
  Manchester twice a year
  Birmingham four times a year

# European Porphyria Registry

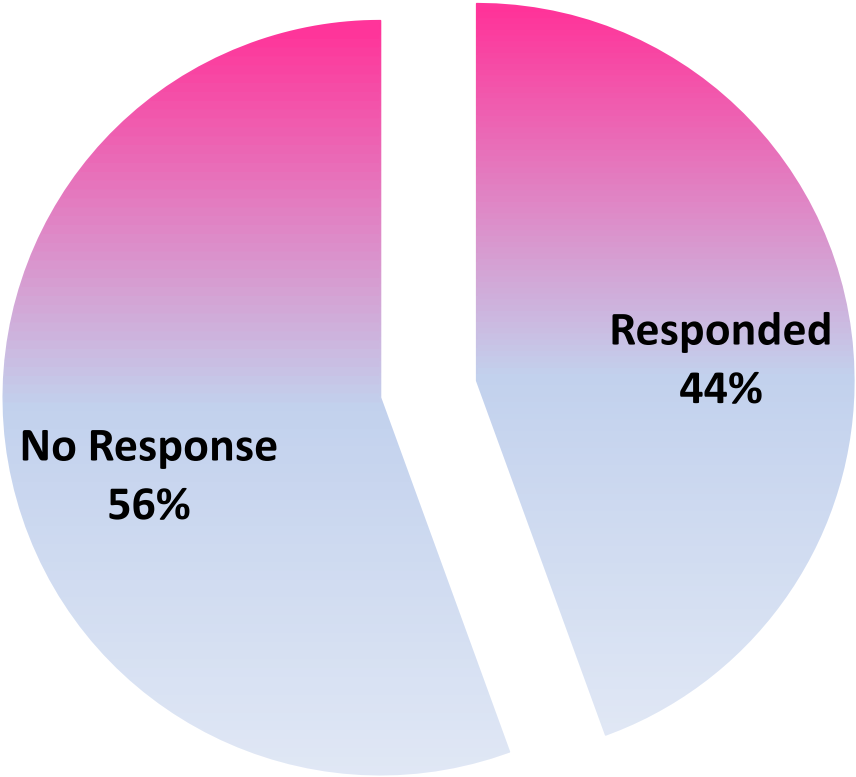
The European Porphyria Registry (EPR) is a project of the European Porphyria Network (EPNET), which is a network of European specialist porphyria laboratories and centres. The aim of EPNET is to improve the lives and healthcare of porphyria patients, and the collection of clinical data is an important part of this work. The EPR is important for two reasons. **Firstly,** the porphyrias are rare diseases and to recruit enough patients to produce high quality research and health care information we need to combine clinical information from across Europe. **Secondly,** by collecting clinical information from patients at regular intervals throughout their lives, we can better understand the course of the disease and assess the success of treatments. The primary aims of the registry are to:

- describe the disease course, diagnosis and treatments for porphyrias,
- investigate the effectiveness of different treatments on the outcome of porphyrias,
- identify appropriate participants for future porphyria related clinical trials.

# Patient Satisfaction Survey

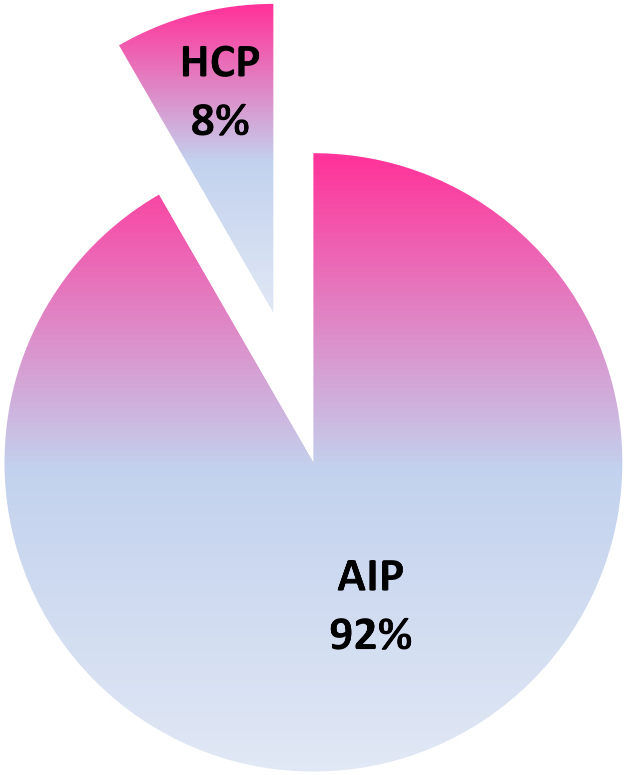
## 2016-2017

# Response rate



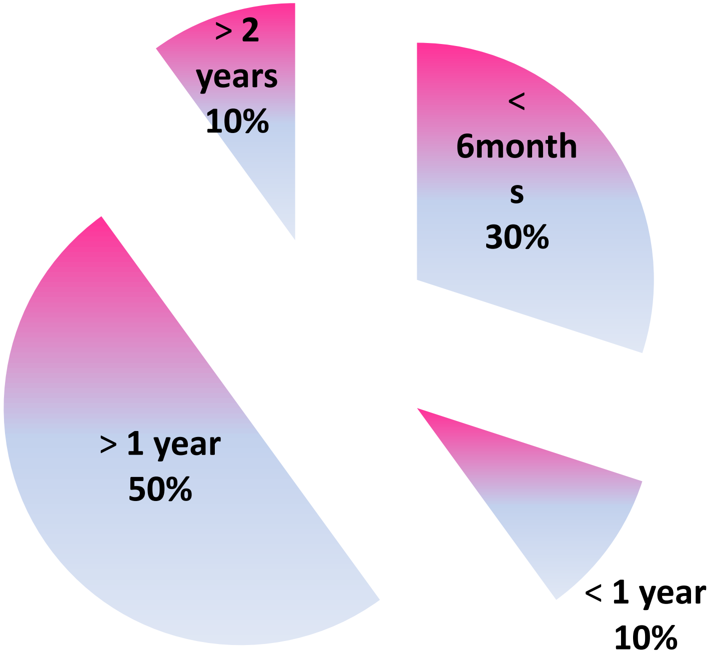
# What type of porphyria do you have?

Response Rate:
100%



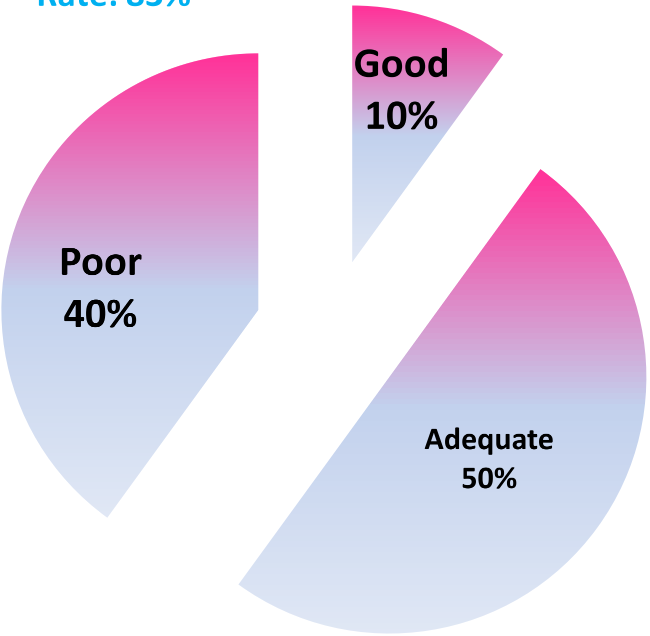
## When did you have your last attack?

Response Rate: 83%



## How would you rate your admission experience?

Response Rate: 83%



# Patients admissions experience

Left in severe pain and vomiting for a long time

I have two years of diaries about my porphyria experience in hospital. You are welcome to copy them if you feel it will help in my care or any other patients.

Smooth admissions process on weekdays, problematic at weekends and evenings

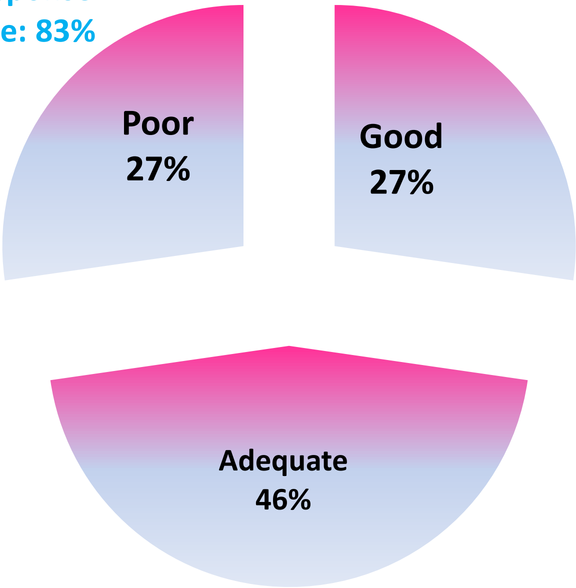
It is improving year after year

Staff are not following the emergency protocol

Reluctant to give me anything but codeine

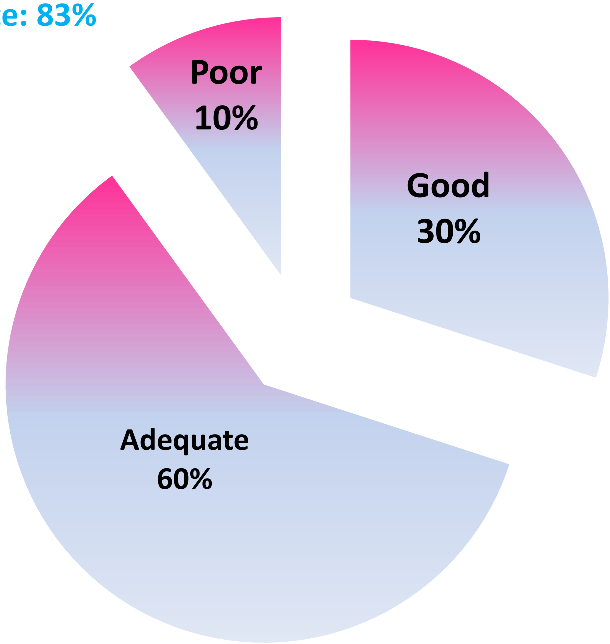
Do not know what porphyria is and in pain for a long time

## How effectively is your pain managed during an admission?



Response Rate: 83%

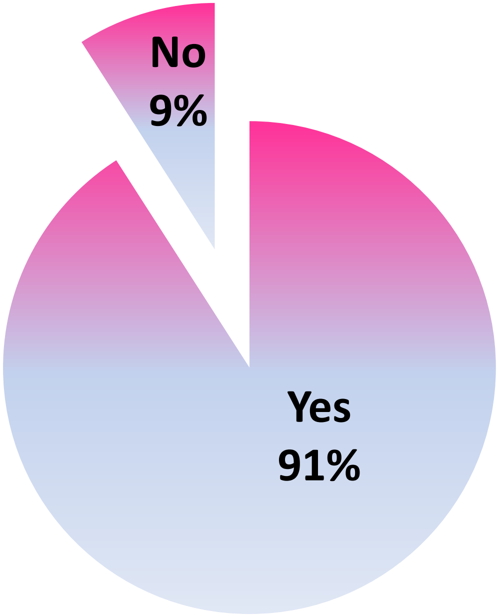
## How effectively is your nausea and vomiting managed?



Response Rate: 83%

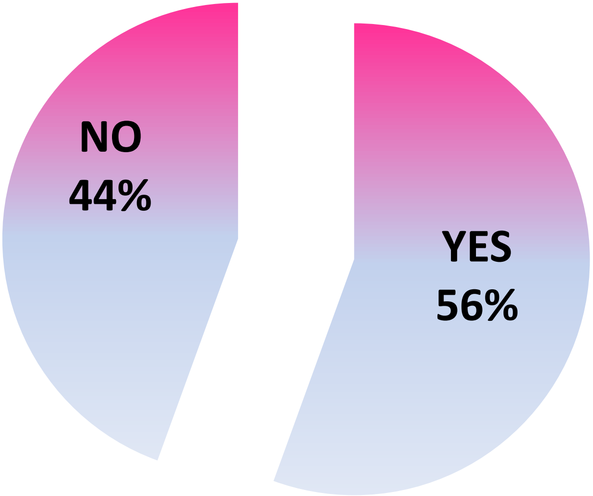
## Do you have an emergency protocol?

Response Rate: 100%



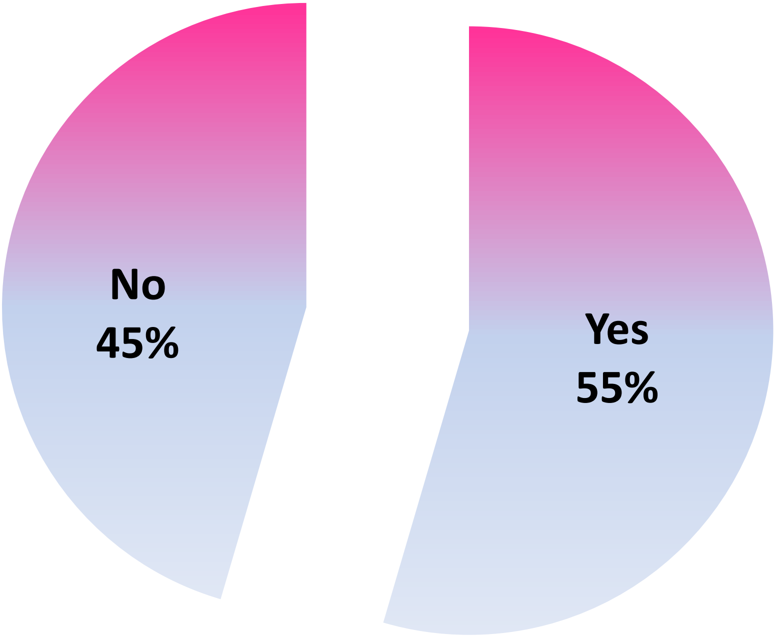
## Does the protocol assist medical staff to initiate appropriate treatment?

Response Rate: 75%



# Do you have a port a cath ?

Response rate:
100%



# How could we improve your overall admission experience?

Educate Whiston staff about porphyria and more options for pain relief and anti sickness

Not enough known about porphyria

More nurses to be trained to access ports

A phone call to the local hospital to back up emergency protocol

Arrange for homecare nurses to administer IV Morphine and Cyclizine to prevent or reduce admissions.

Staff are taking too long to administer pain relief and anti- emetics

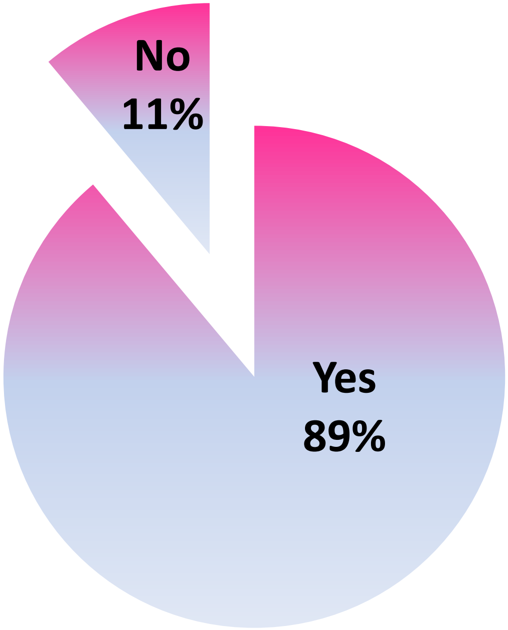
Let me be hands on with my own protocol

No PBG results given (suggest text alert if sample received)

# Outpatient visit survey

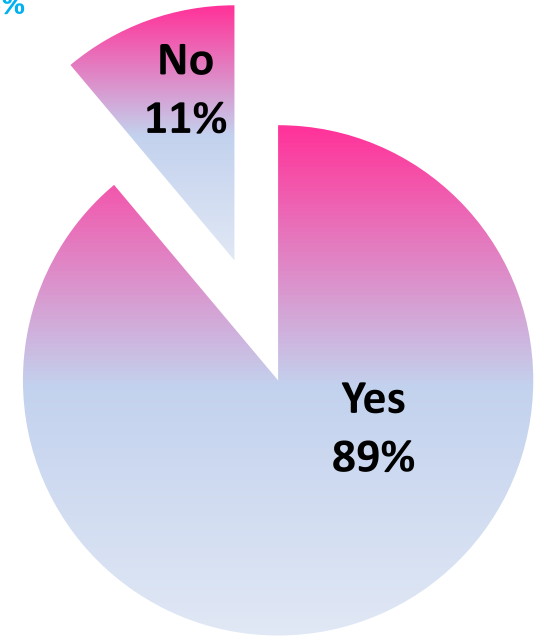
## Did you get to meet the NAPS specialist nurse?

Response Rate: 75%



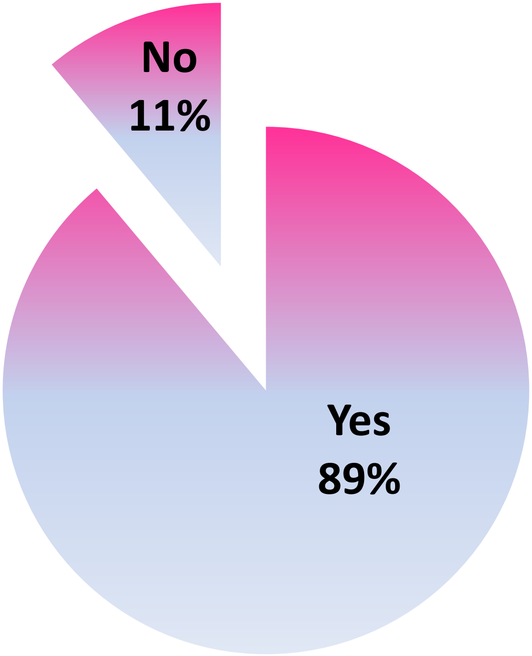
## Did you receive written information about porphyria?

Response Rate: 75%



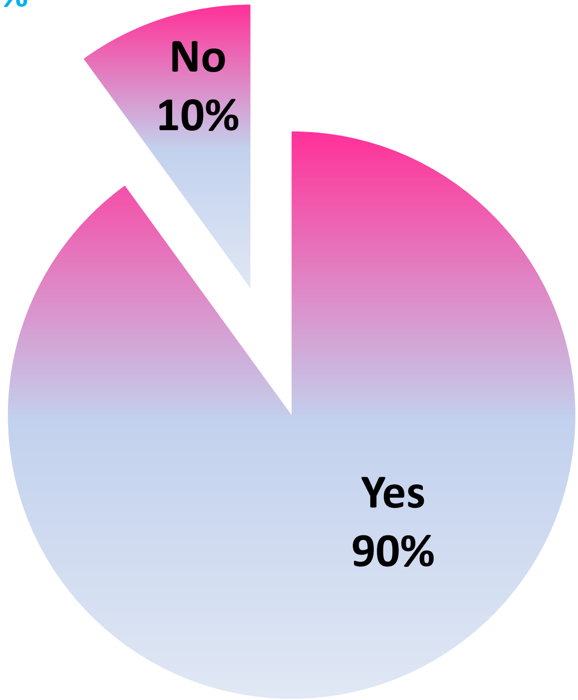
## Do you receive a copy of the clinic letter following your visit?

Response Rate: 75%



## Are you aware of the British Porphyria Association?

Response Rate: 75%



# Positive feedback

Very pleased with improved service since NAPS commenced.

Porphyria urine pack is all I could ask for, helps to know if its an attack and can give me appropriate treatment faster.

I have always found Dr Badminton and Tricia Gardiner very approachable, kind, considerate and professional at all times.

Thank you for the support, particularly being available to talk on the phone when needed.

I don't think you can do more then you already do.

The admissions are improving year after year.

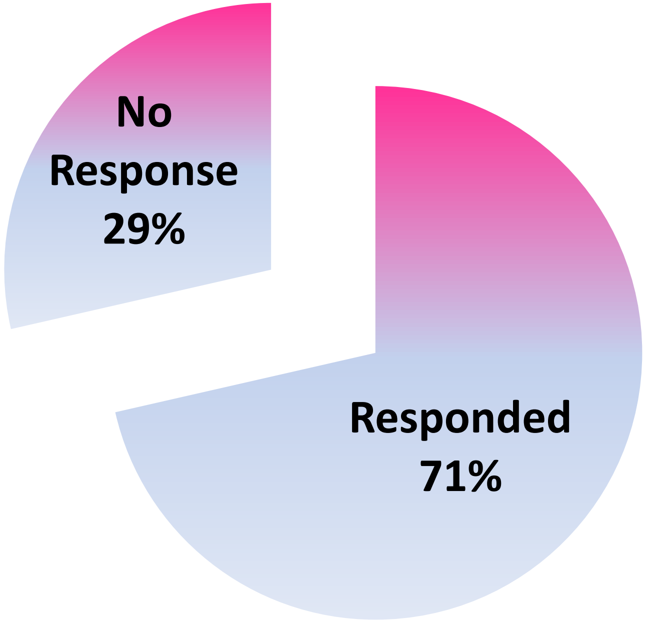
Homecare provide an excellent service.

No improvements needed, I have always felt in good care.

# Lloyds pharmacy clinical homecare

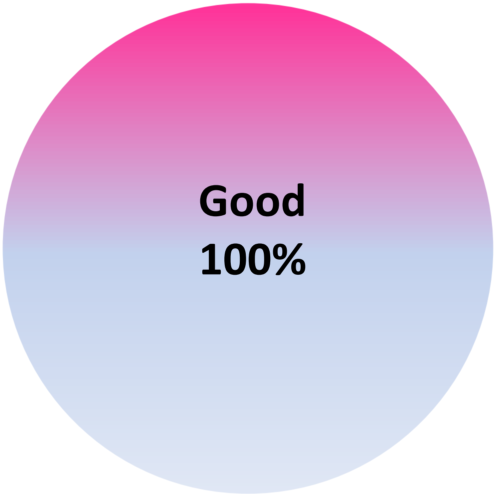
7
questionnaires
sent out

5 responses



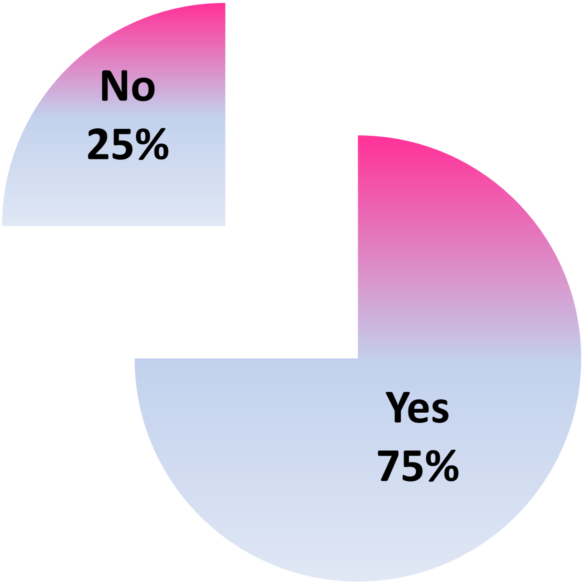
## How would you rate the homecare service overall?

Response Rate: 100%



## Do you know how to contact homecare if you are not happy?

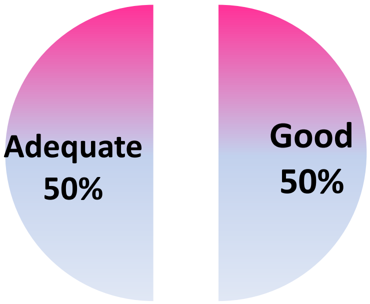
Response Rate: 80%



# Customer Service Team

## Punctuality of your delivery

Response Rate: 80%

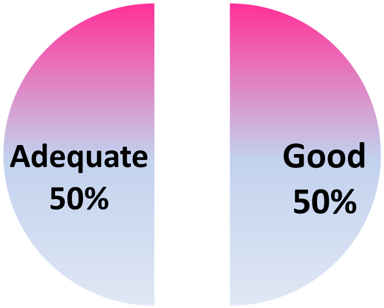


## Accuracy of supplies delivered

Response Rate: 80%

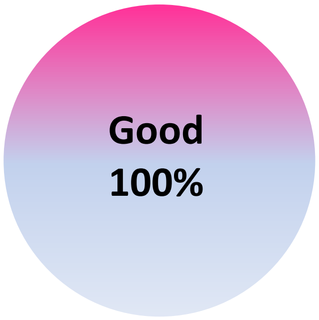
## Collection of waste

Response Rate: 80%

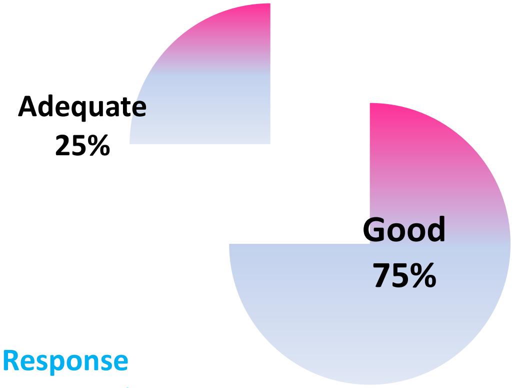


## Ease of contacting the customer service team

Response Rate: 100%

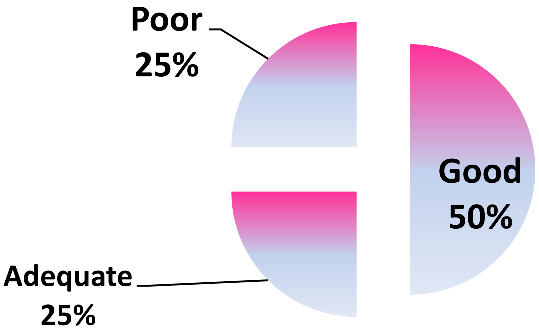


## Receiving a message to confirm delivery



Response Rate: 80%

## Handling of concerns or complaints



Response Rate: 80%

# Nursing Service

## Training provided by the homecare nurses

Response Rate: 80%

**Good**
**100%**

## Professionalism of your homecare nurse

Response Rate: 80%

**Good**
**100%**

## Support from your homecare nurse in helping manage your treatment at home

Response Rate: 100%

**Good**
**100%**

# Summary

Confirms that patients still value NAPS

Homecare improves patient's quality of life

**Patient concerns**

Delay of appropriate pain relief and anti emetics in emergency unit

Delay in contacting NAPS on admission

Emergency protocol not adhered to in some health boards

# Clinical Nurse Specialist Role

- Support : empathy and responsiveness to the wishes and concerns of patients and their families
- Avoid risk factors and manage symptoms
- Awareness of governance issues that reflect safe practice
- Patient advocate
- Caring complex problem solver with good leadership skills
- Effective clinical decision making skills
- Specialist nursing interventions improve quality of care
- Collaborate with local teams