



A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline

Children's Palliative Care Networks: Benchmarking Charts



# The Charts



- Representatives from each network completed the survey
- Some networks asked for more than one person to answer the survey
- 19 questions were based on the NICE guideline baseline assessment; 5 were based on specialised commissioning
- The interviewees gave the frequency about how often they achieve that statement across their region/country.
- The answer formed the basis of a report to NHS England.
- Each network can benchmark themselves against the other networks (you will be provided with your network's identification separately).

# Benchmarking



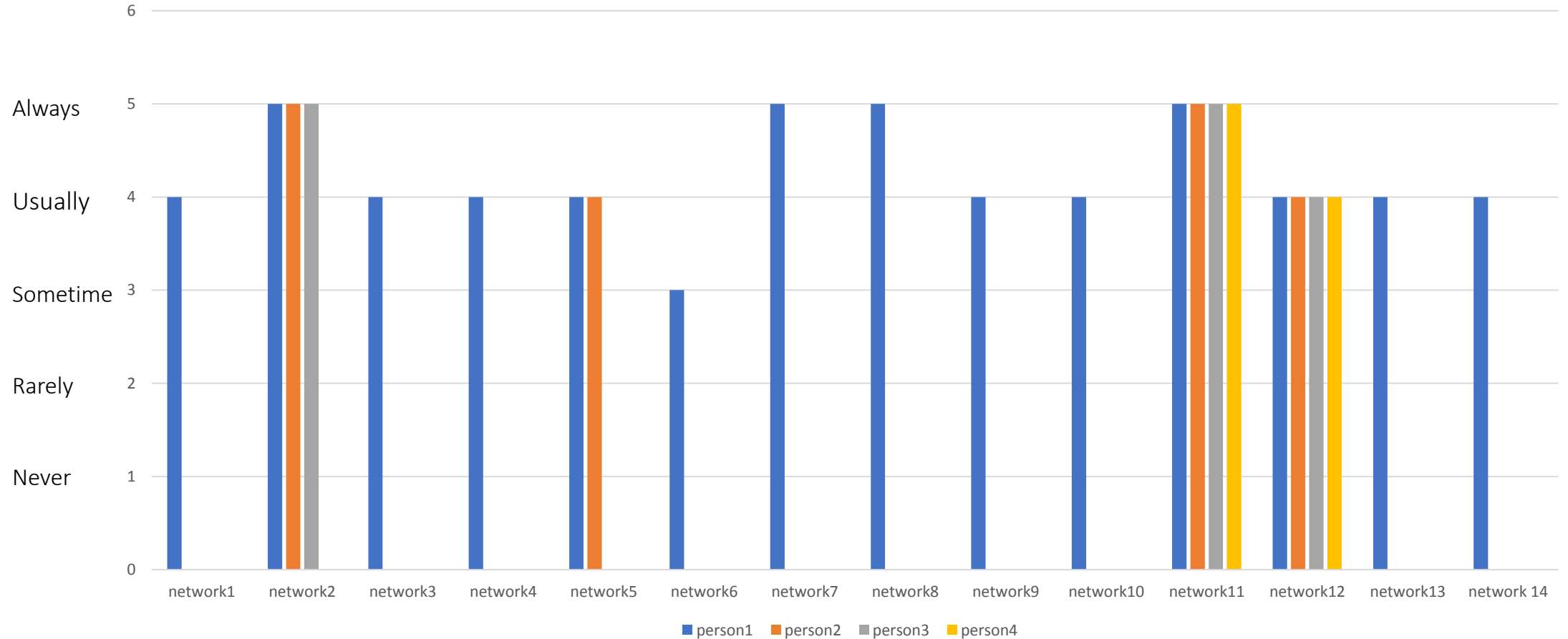
- Benchmarking is “a systemic process in which current practice and care are compared to, and amended to attain, best practice and care” (DH 2010)
- A number of resources are available to support benchmarking activity and are referenced at the end of this series of slides

# How to use the charts

- The following series of charts provides the responses given by networks.
- Networks may wish to benchmark regional practice against other networks; some networks provided responses broken down into smaller geographical areas and may wish to compare and contrast practice within the region.
- Where you have achieved best score, share your practice with others and consider including this in the Together for Short Lives Compendium of Local Solutions
- Where you have not achieved best score, review examples of other local solutions
- Consider drawing up a development plan to address gaps in service

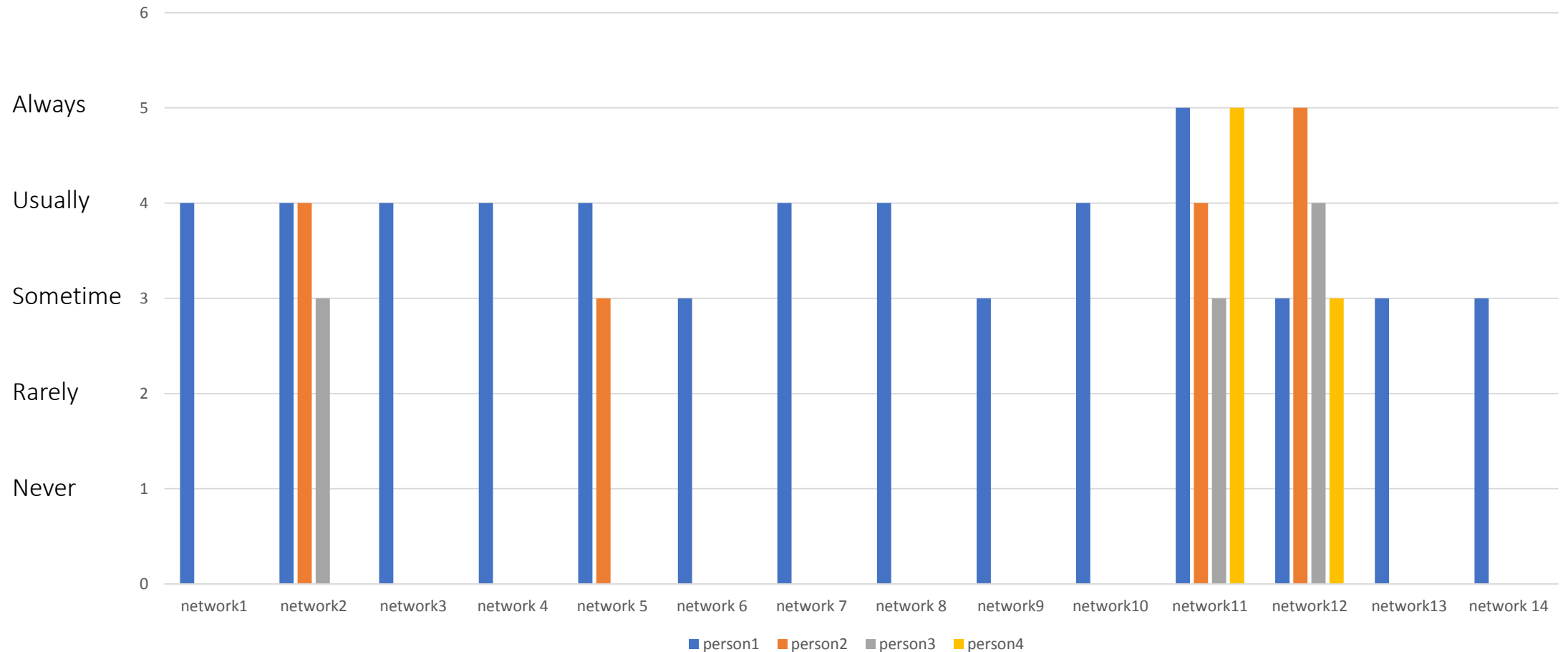
# Communication between professionals/parents:

Professionals think about how best to communicate with each child or young person and their parents or carers



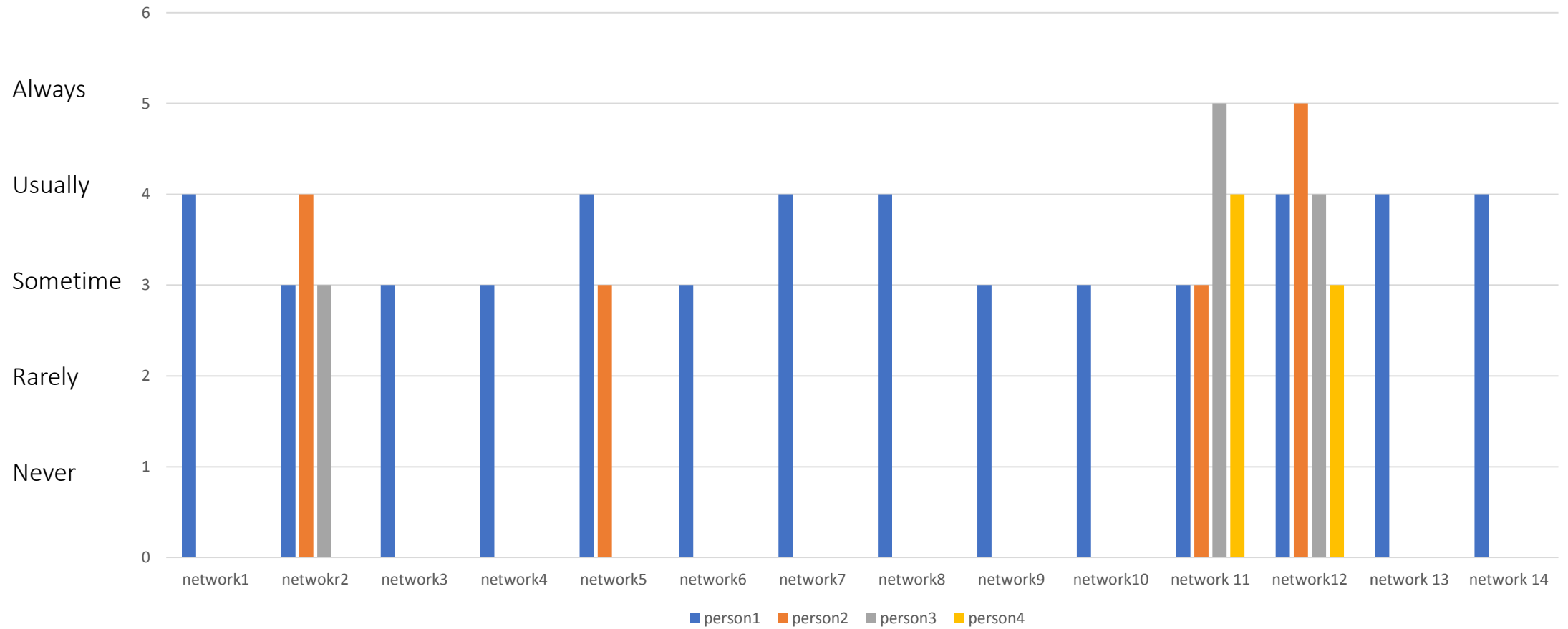
# Communication between professionals:

Services within all relevant agencies engage in planning for the specific needs of the child/young person



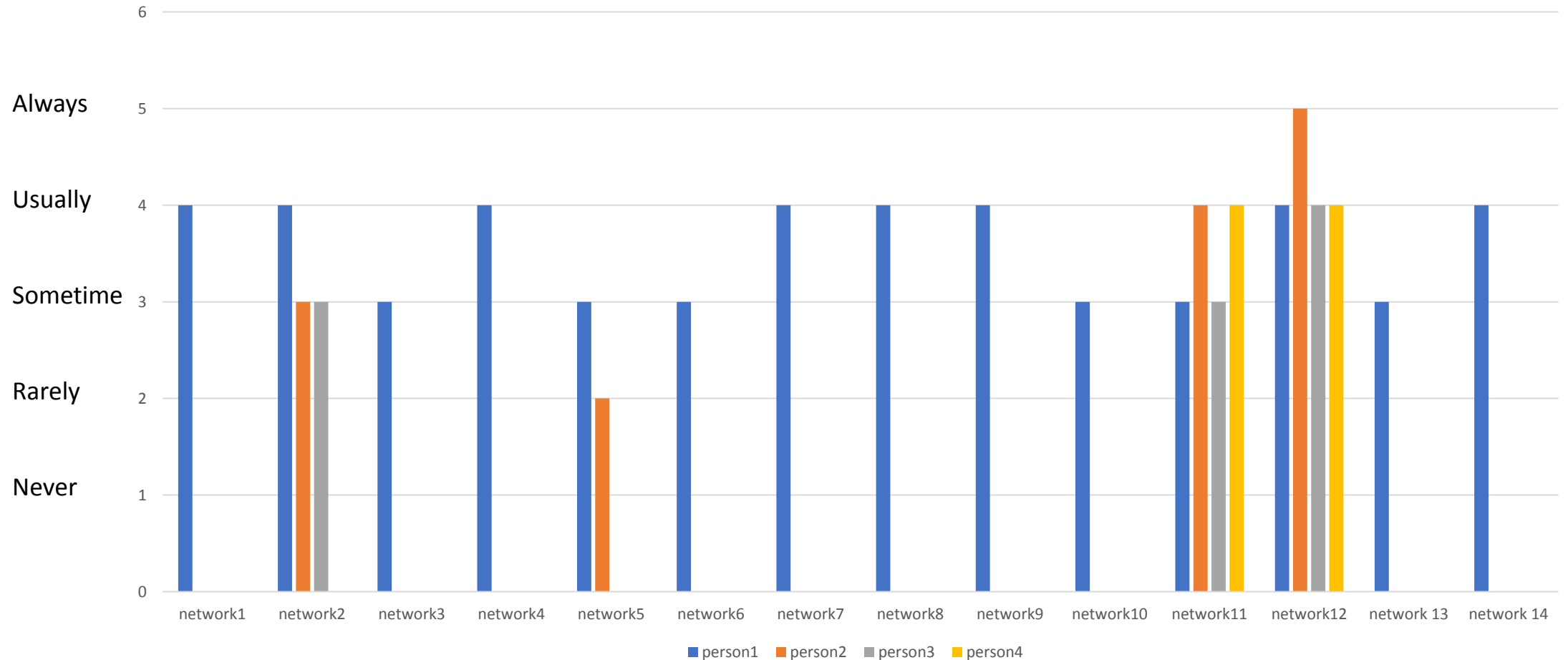
# Information available:

Children, young people and their families have easy access to information about their condition and services available to them



# Advance care plans:

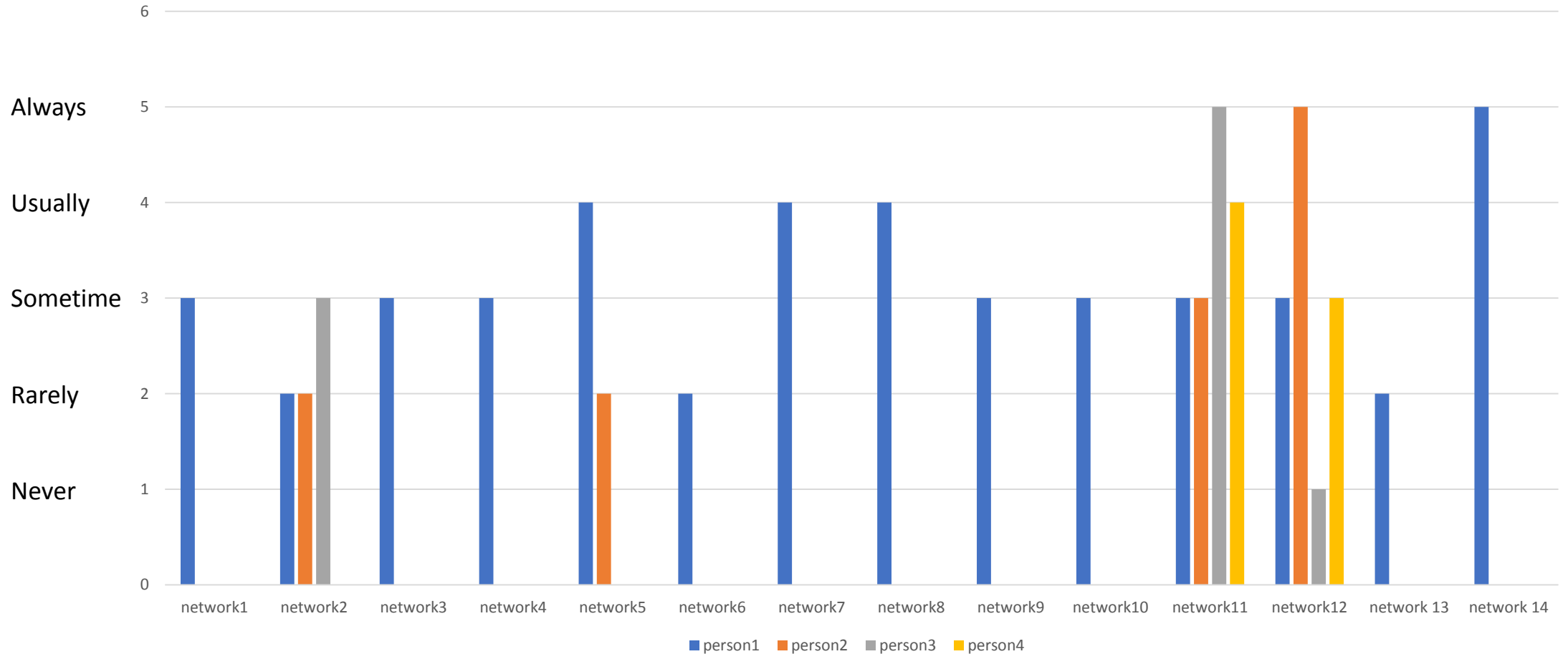
Each child or young person and their family has an Advance Care Plan or equivalent





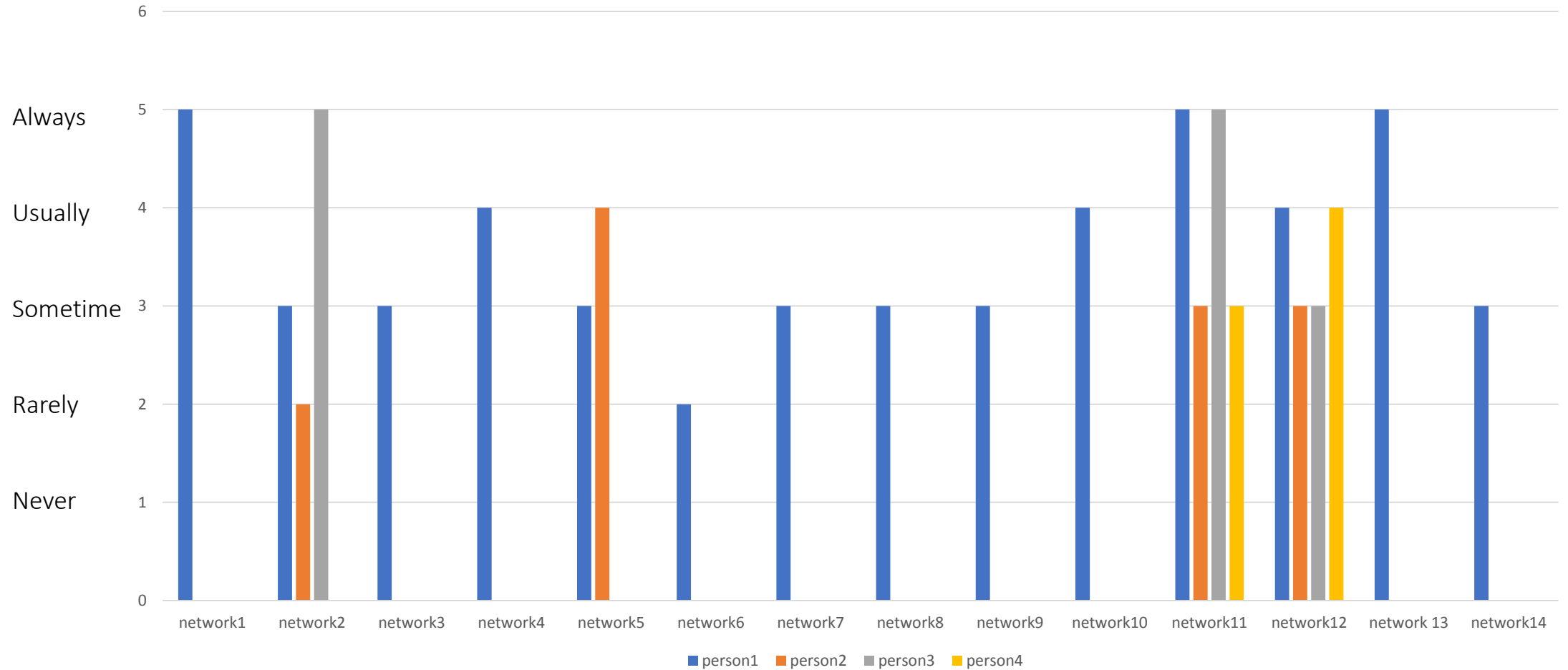
# Emotional/psychological support

Is available for children and young people with a life-limiting condition



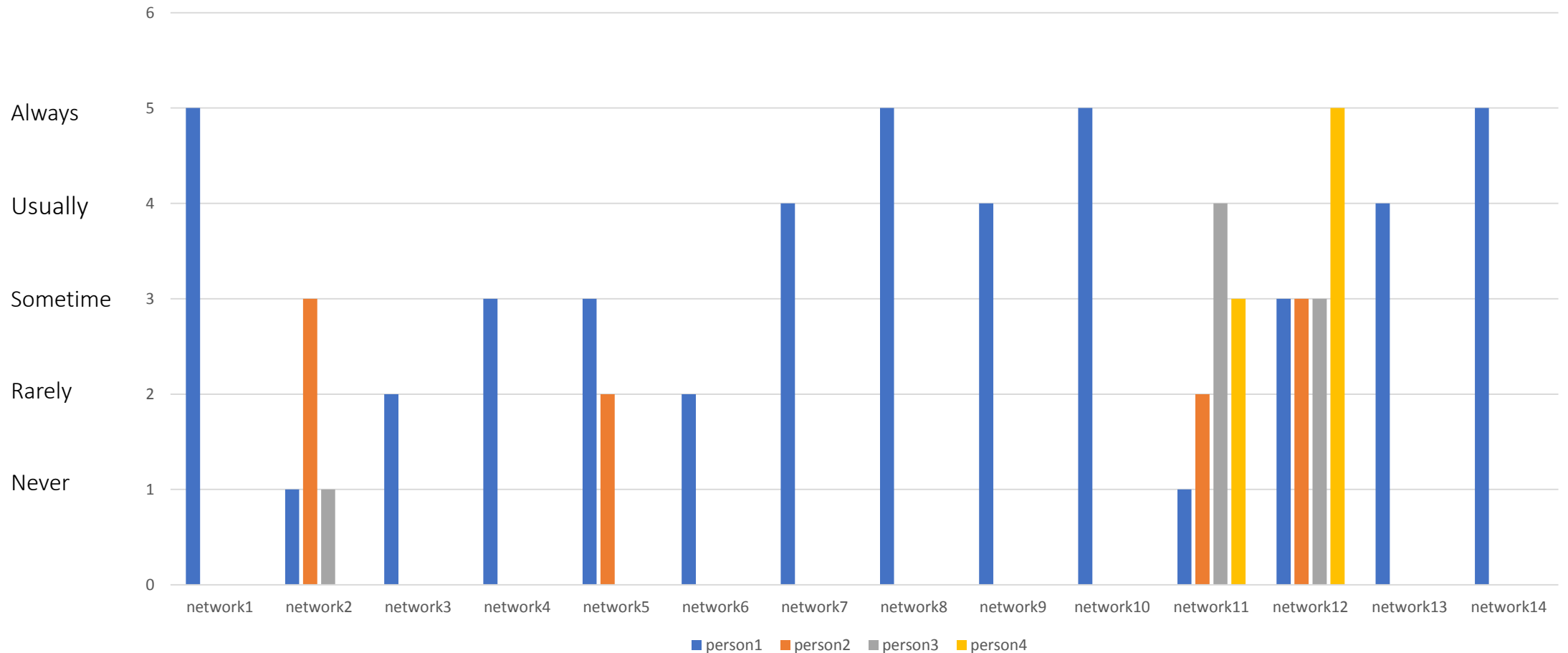
# Religious/spiritual support

Is available for children and young people with a life-limiting condition.



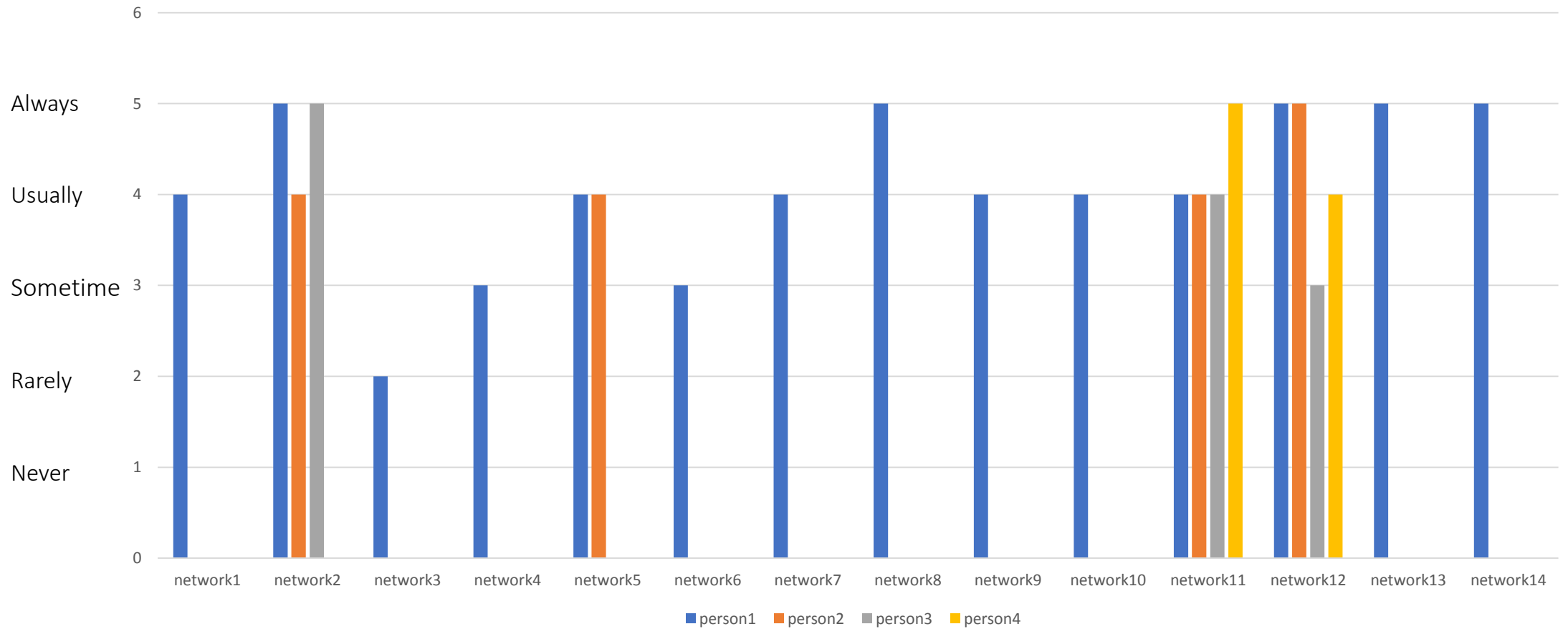
# Symptom management:

Staff have 24/7 access to specialist advice on complex symptom management in children and young people



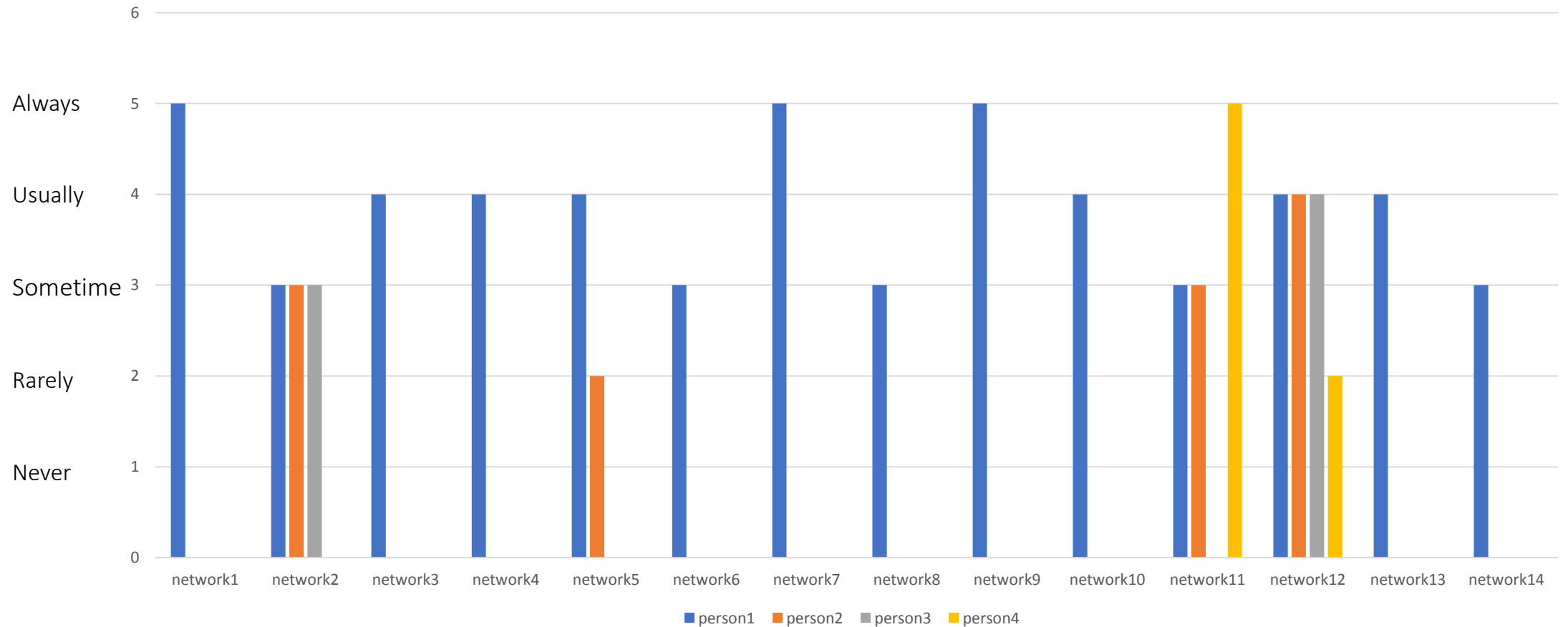
# MDT:

Children and young people with life-limiting conditions are cared for by a defined multi-disciplinary team



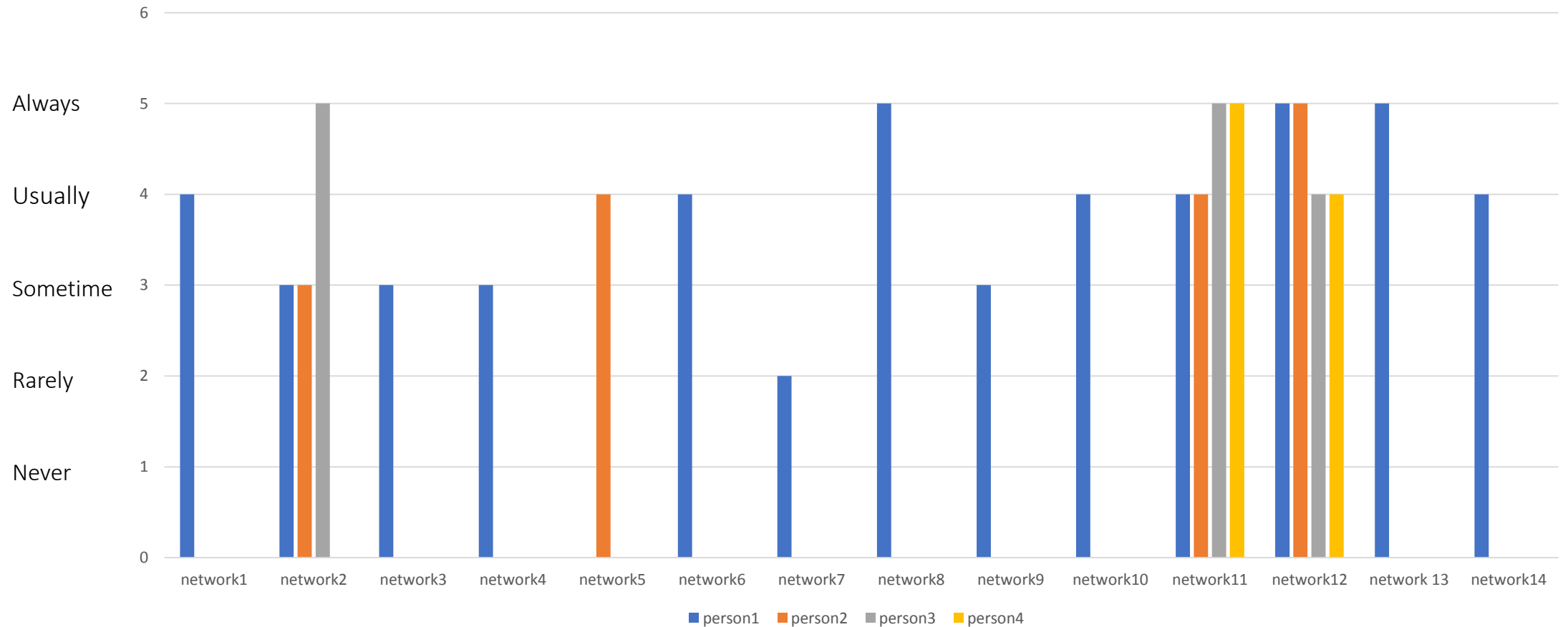
# Family support:

Care plans address the care and support needs of all immediate family members



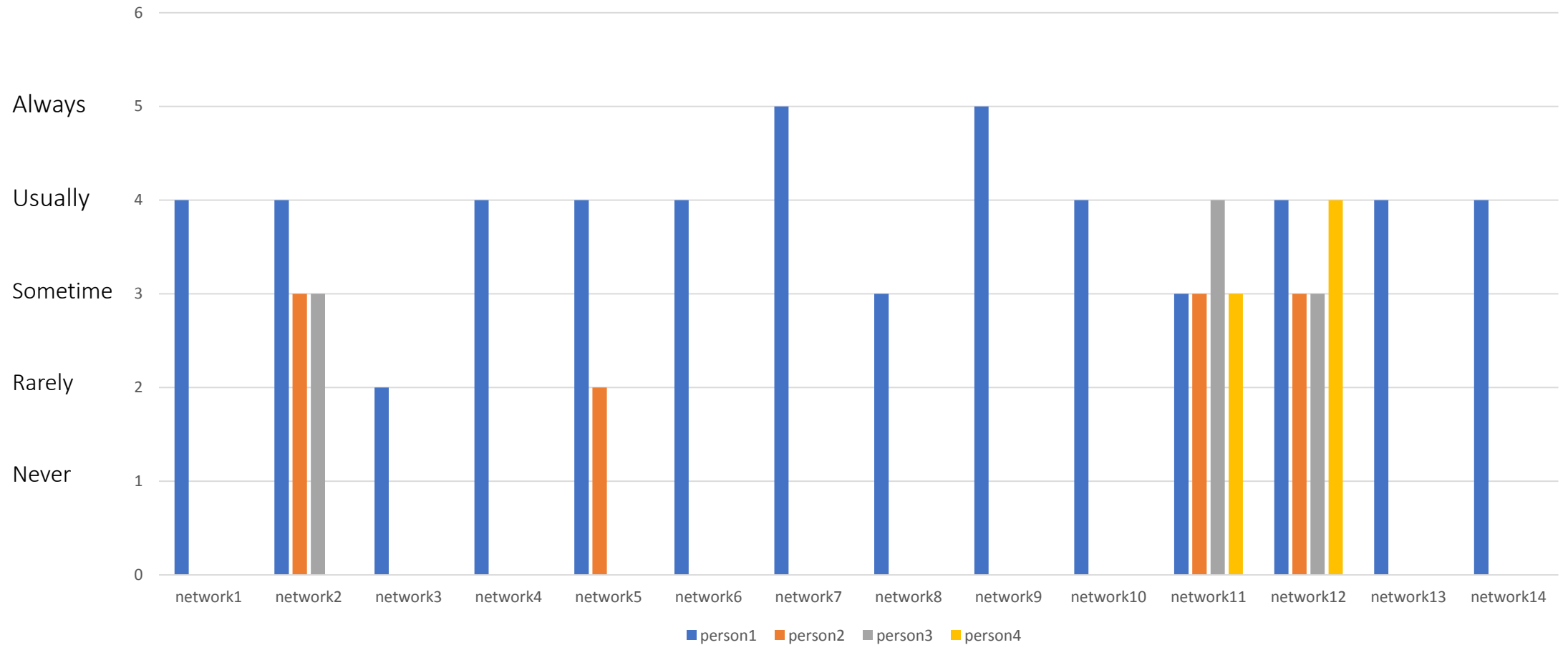
# Organ and tissue donation:

Processes are in place for families to discuss their preferences for organ and tissue donation



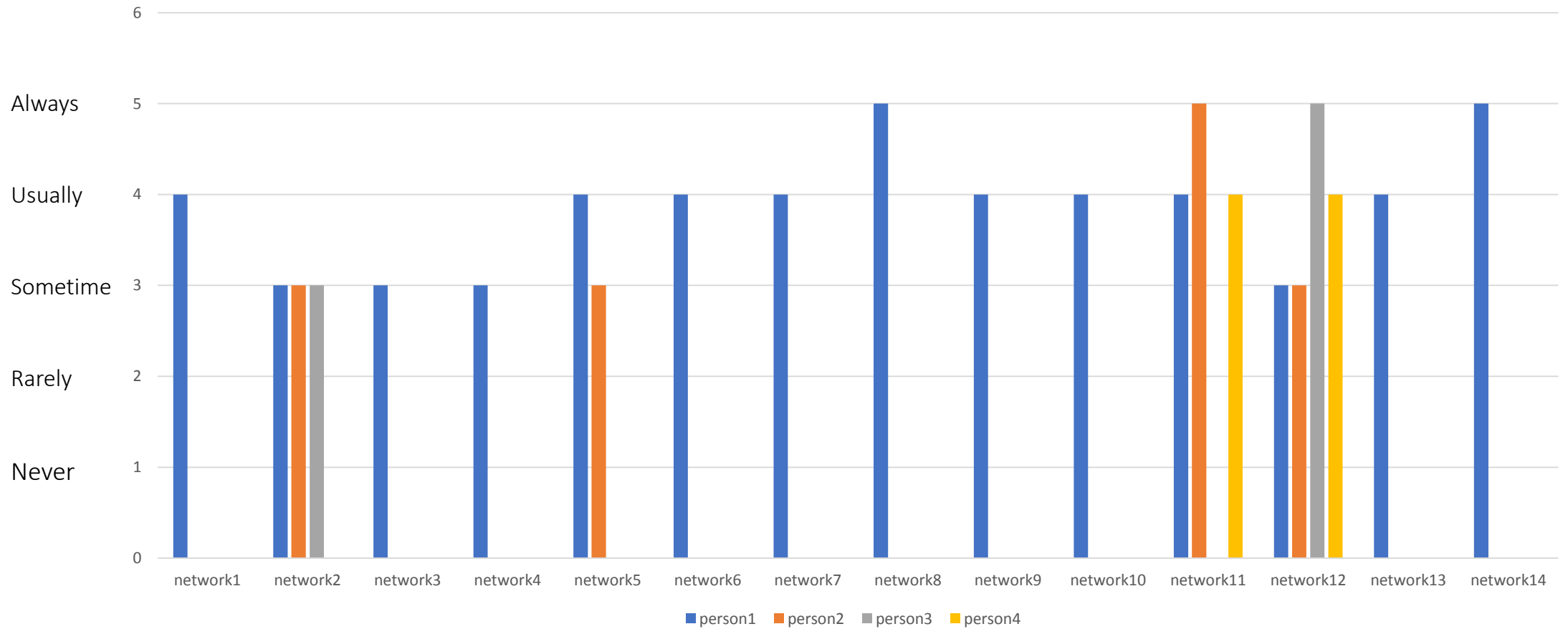
# Recognise likely to die:

Professionals are able to recognise when a child is likely to die within the next few days



# EOL care:

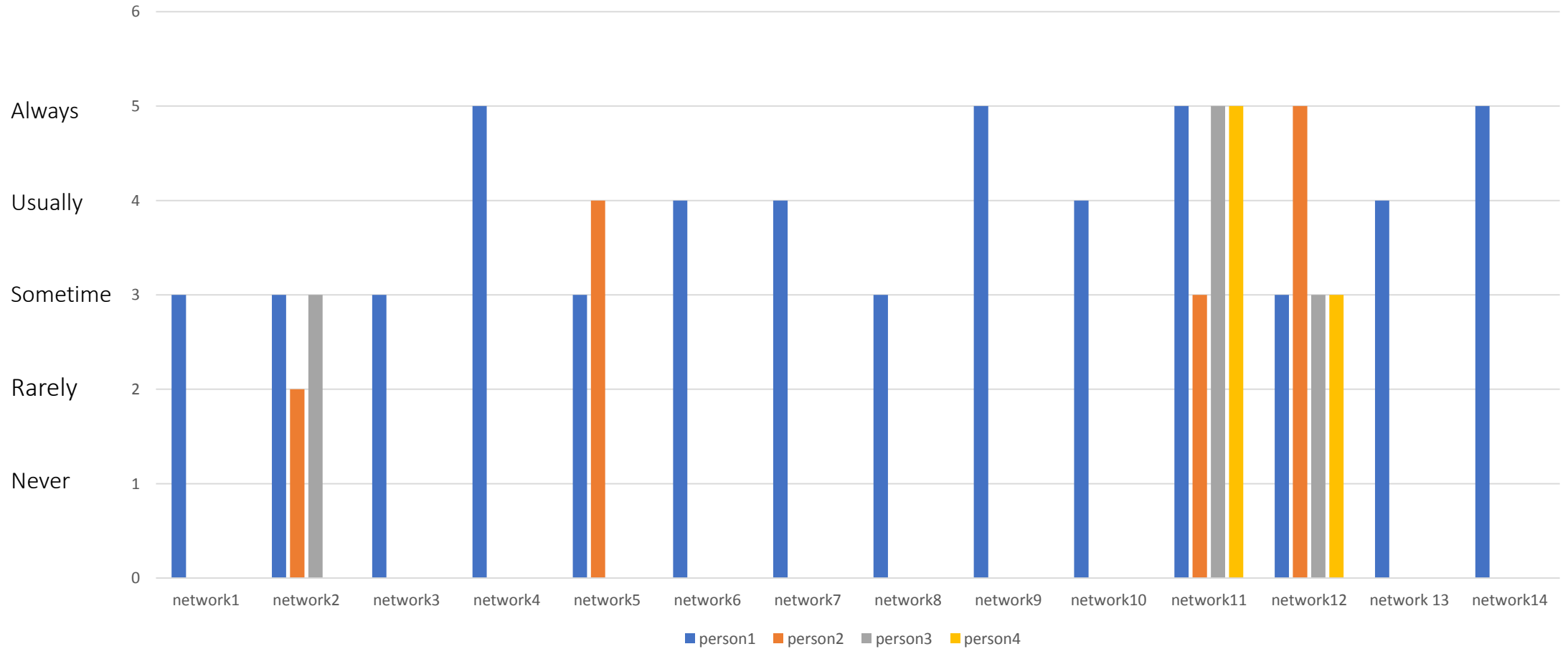
Every child and family has an end of life plan when appropriate





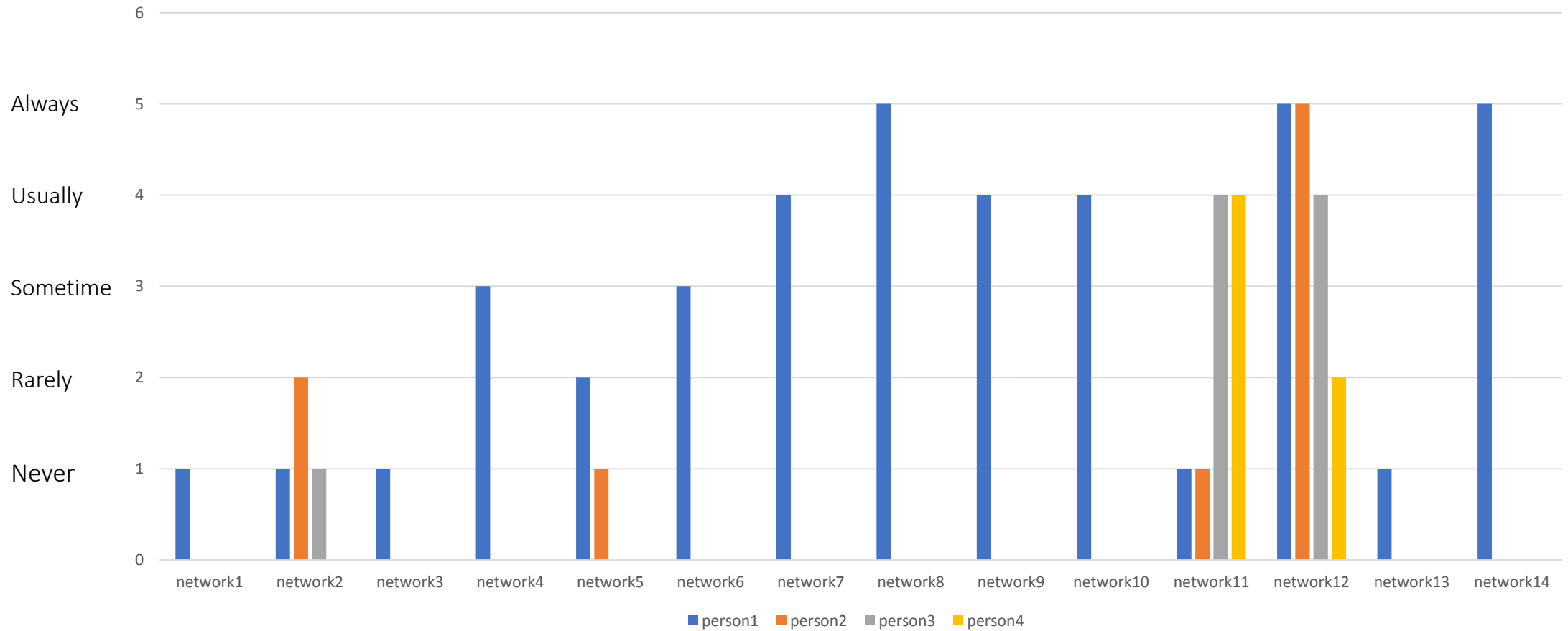
# EOL care:

Every child approaching the end of life has 24-hour access to paediatric nursing care



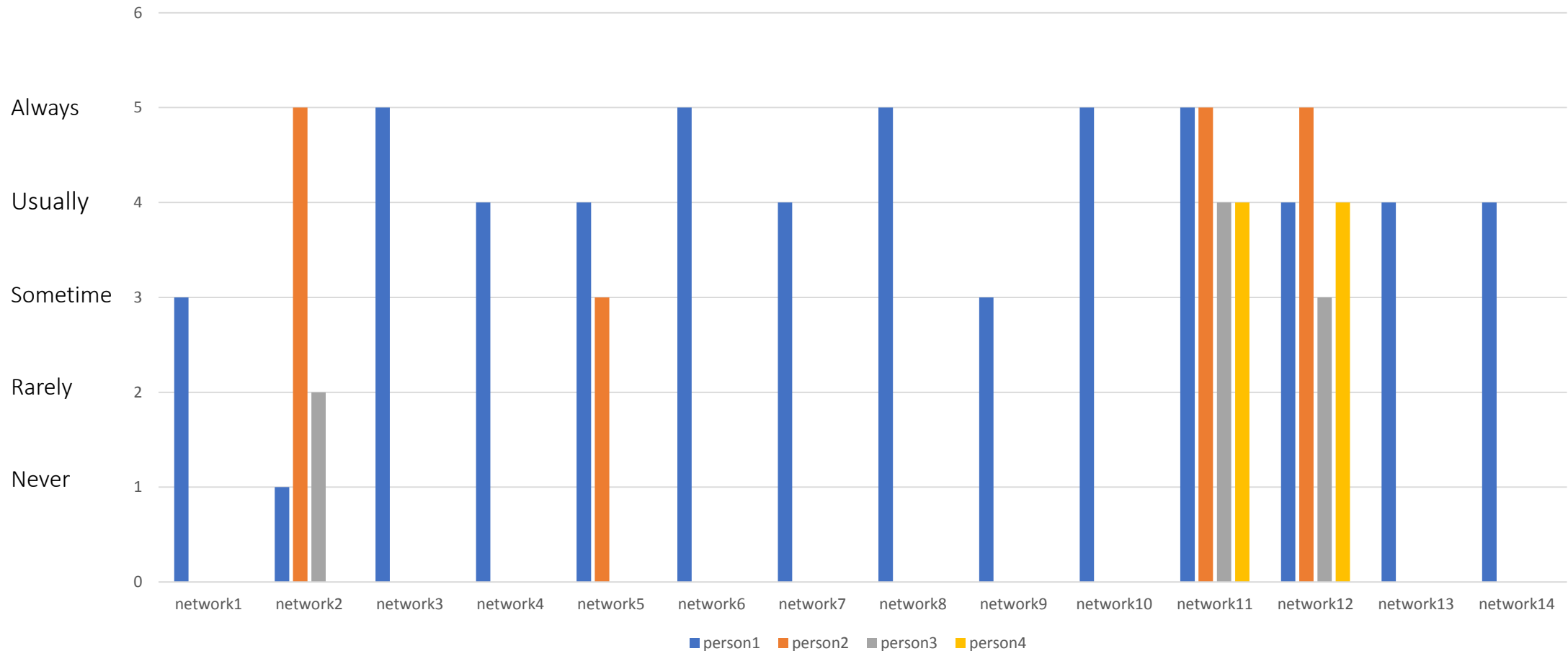
## EOL care:

The carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care.



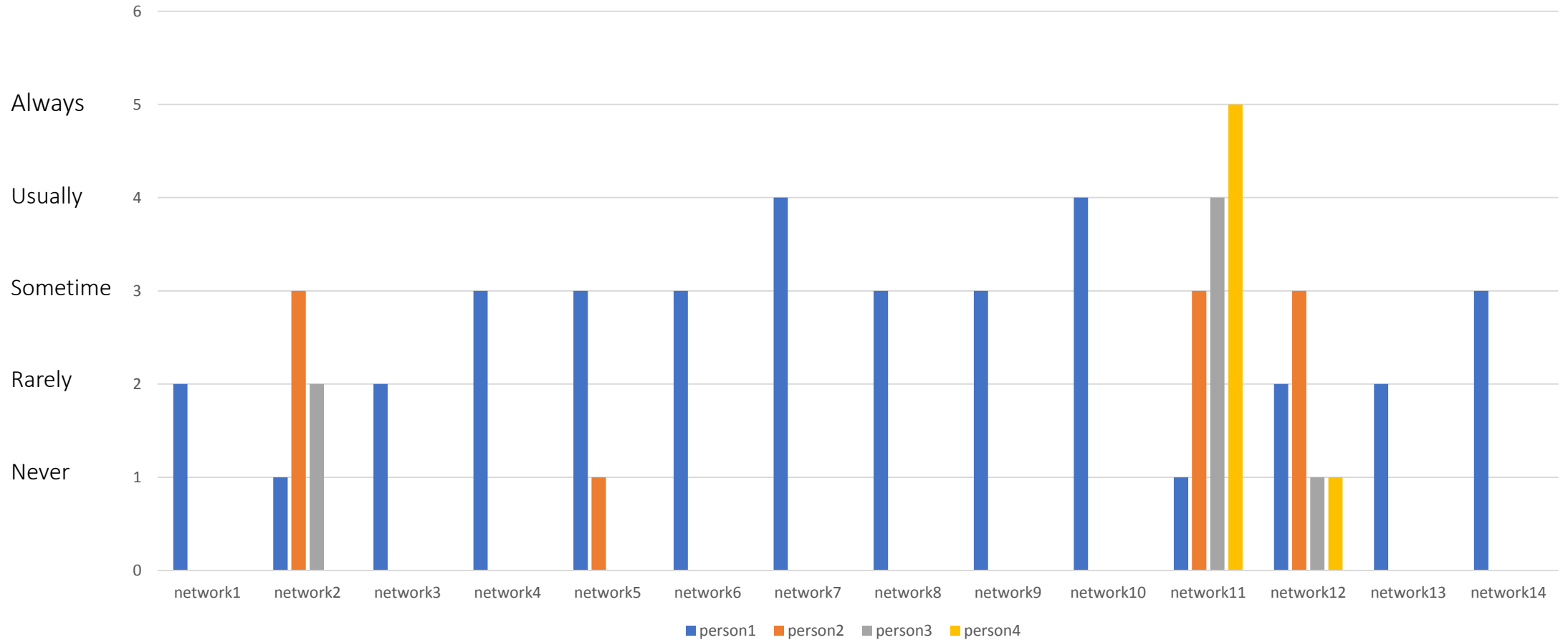
# Rapid transfer:

There is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care



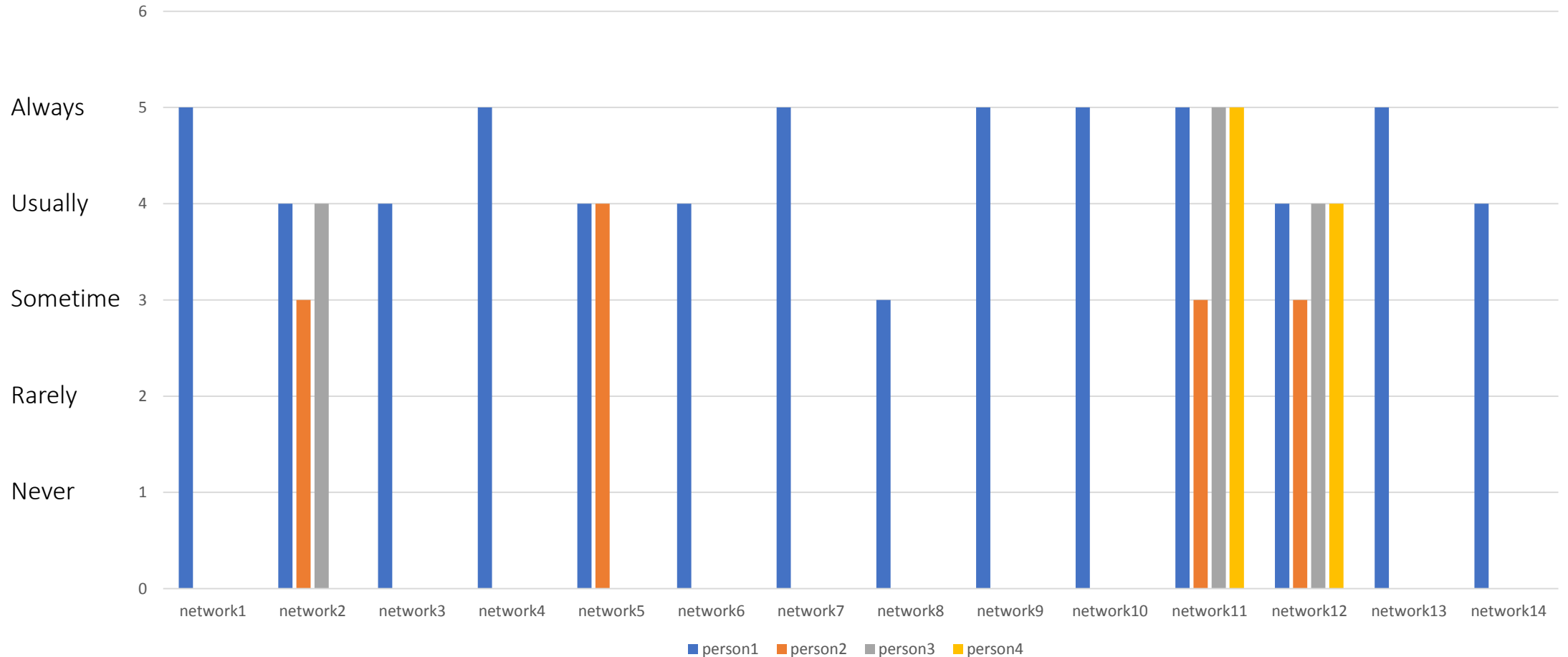
# Care at home:

Every child has access to a 24 hour multi-disciplinary children's palliative care team for care within the home



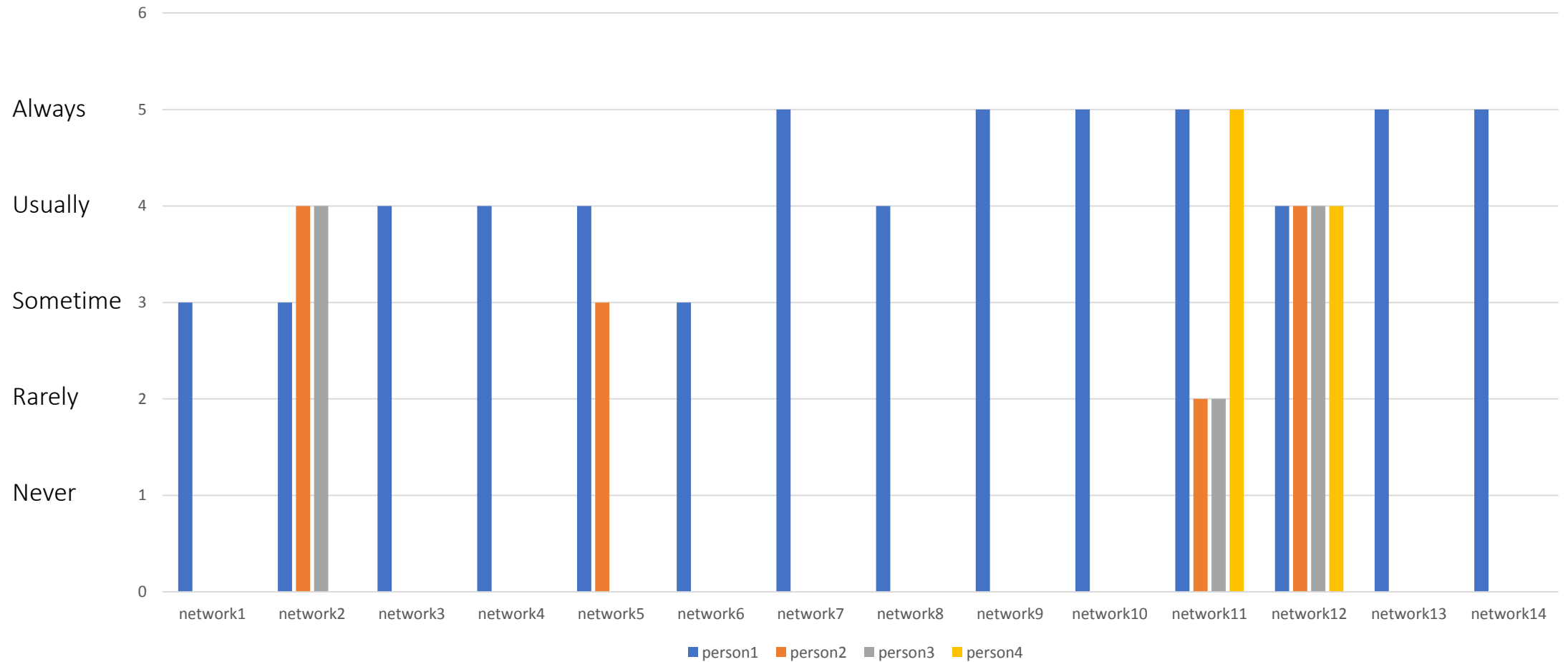
# Care after death:

The practical arrangements that will be needed after the death of their child are discussed with parents/carers



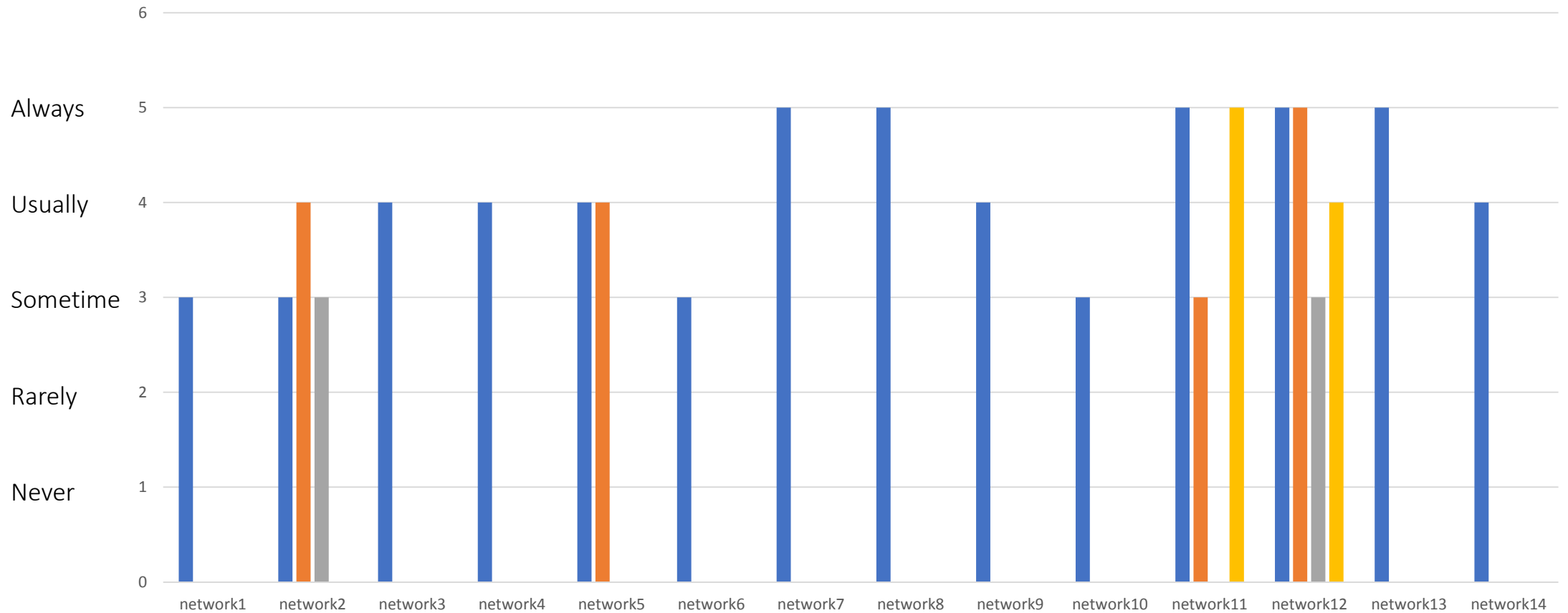
# Staff support:

Professionals have access to ongoing support and supervision



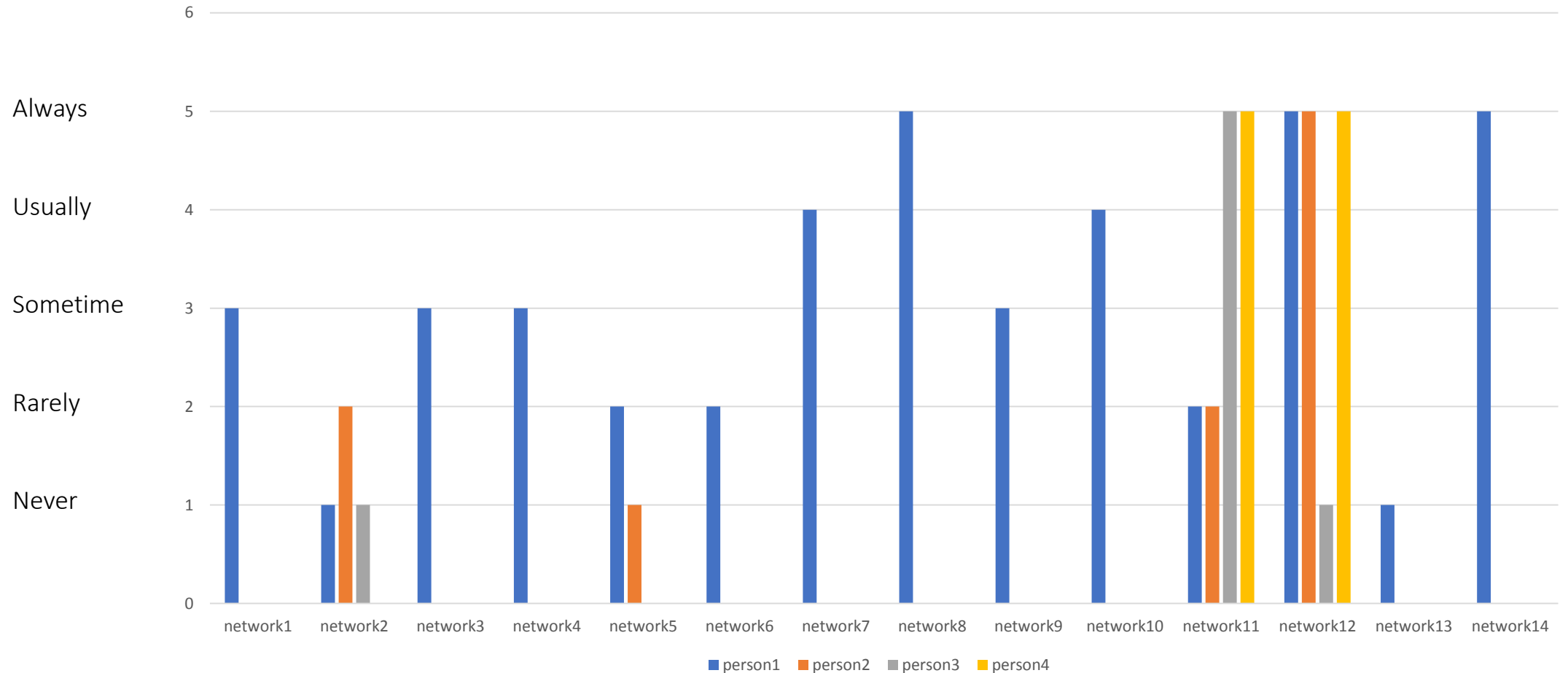
# Bereavement support:

Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death



# Specialist paediatric palliative care team:

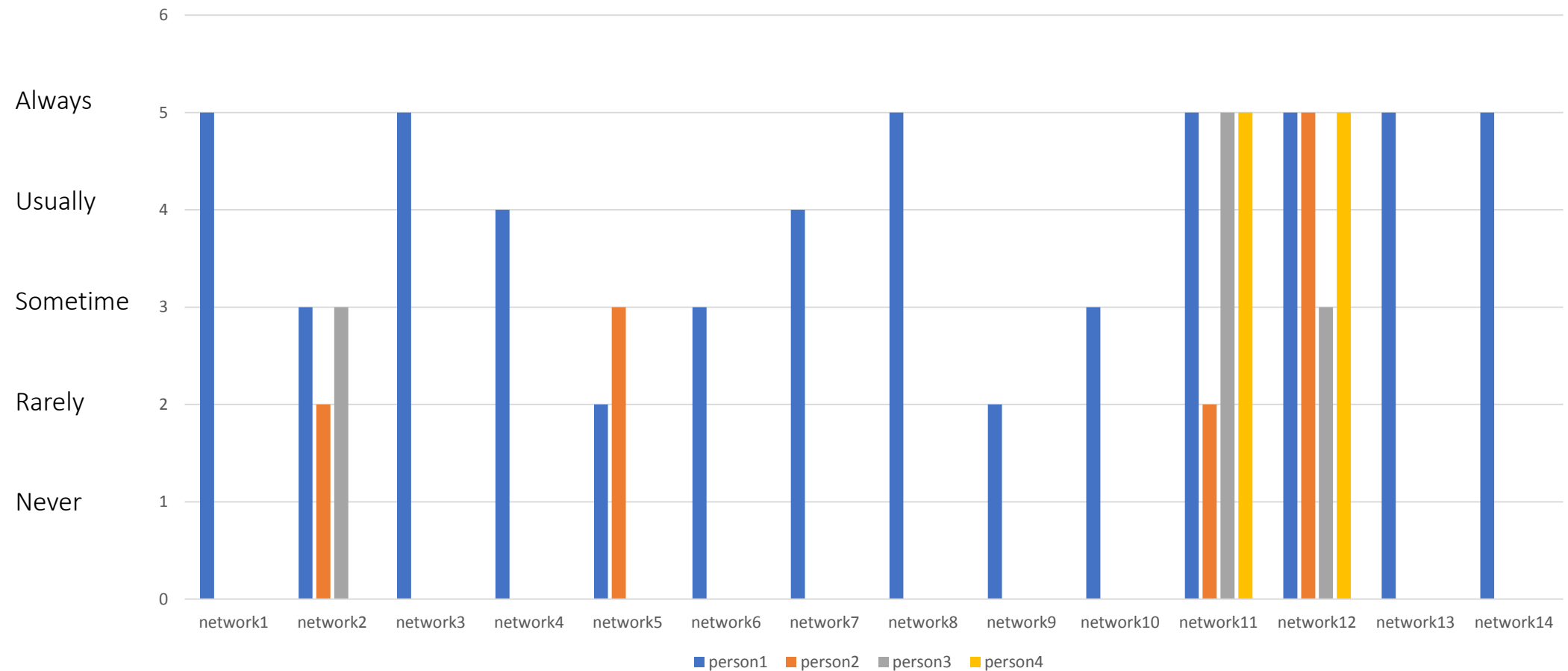
Service delivery is provided by a consultant-led multi-professional specialist palliative care team across the network/MCN





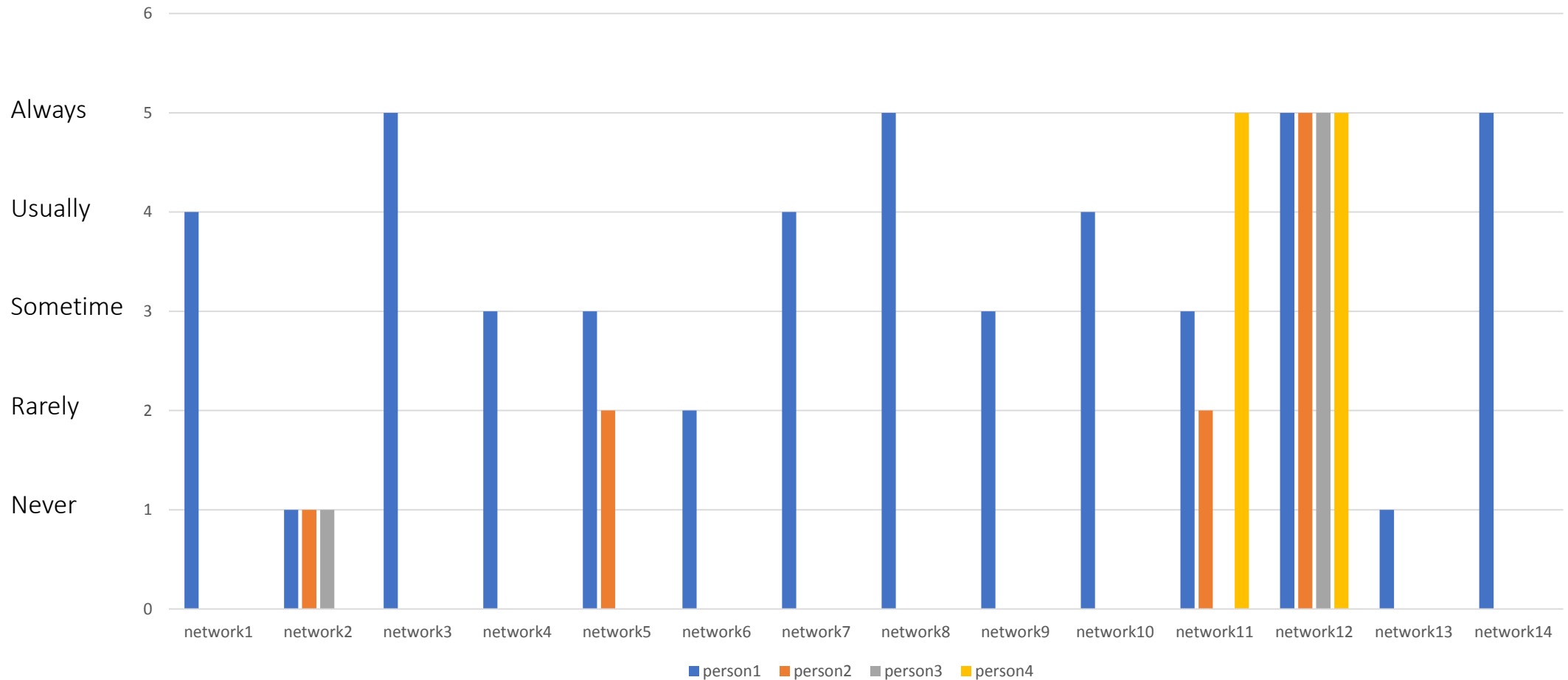
# Specialist paediatric palliative care team:

There is a clinical leadership role in planning delivery and evaluation of children's palliative care services across a network/ managed clinical network



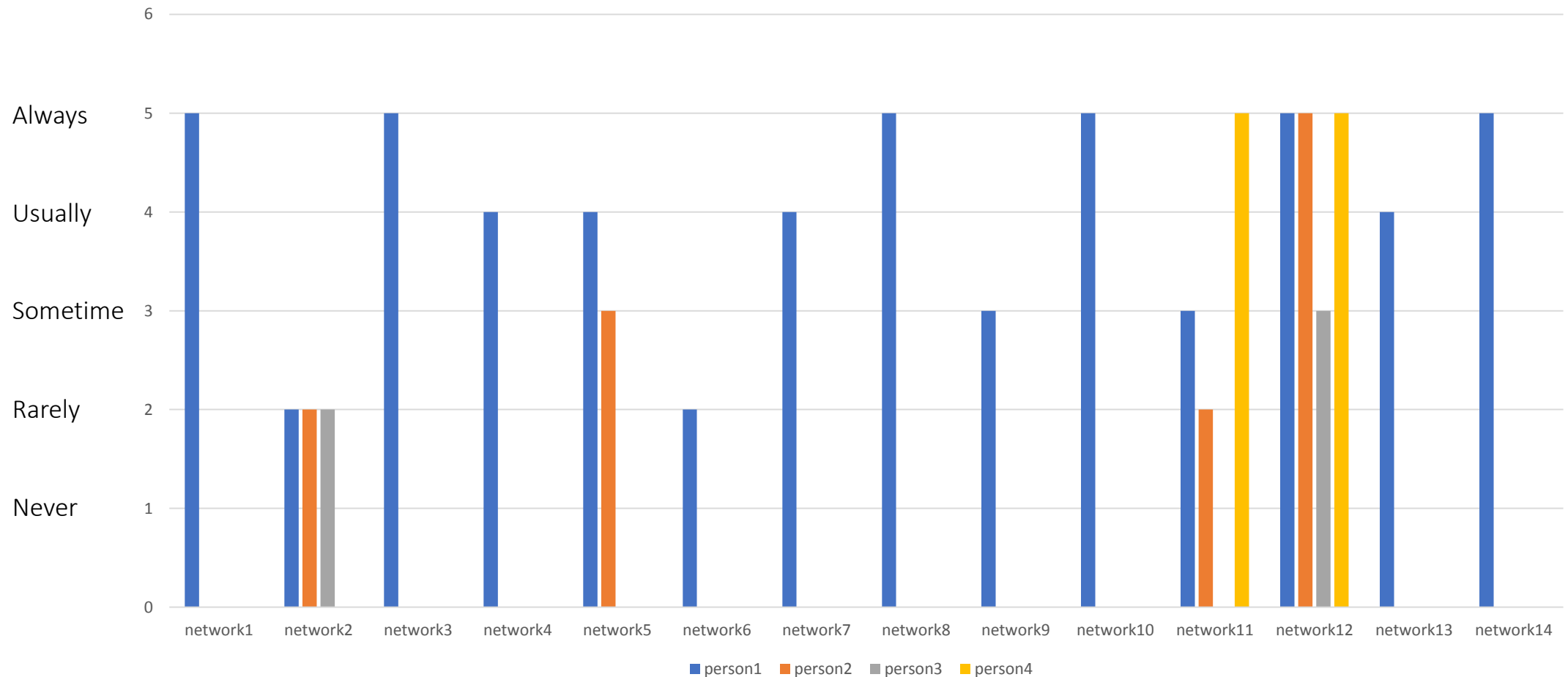
# Specialist paediatric palliative care team:

Care is led by a medical consultant working at Paediatric Palliative Care Competency Level 4



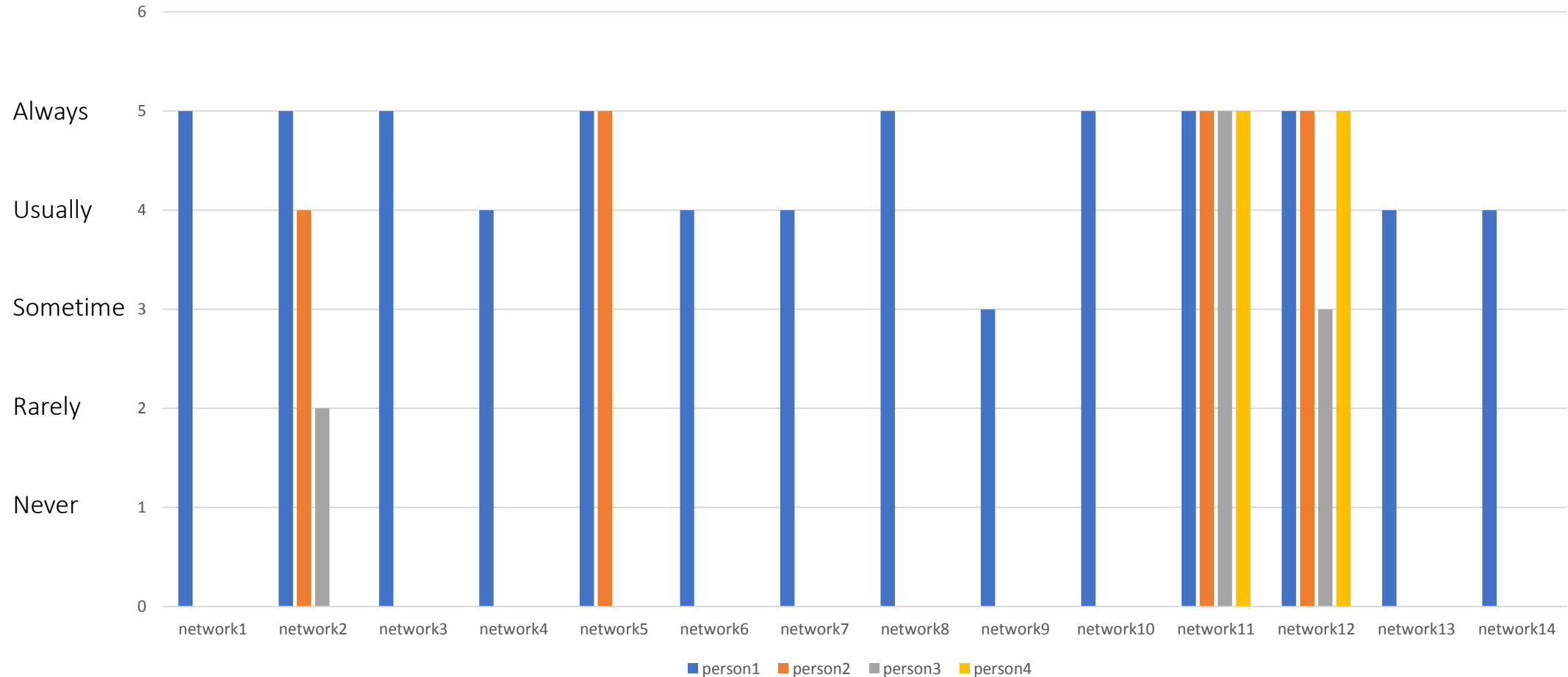
# Specialist paediatric palliative care team:

The MCN/network provides the full range of specialist paediatric palliative care interventions including use of alternative opioids



# Specialist paediatric palliative care team:

The MCN/network are able to treat all children and young people, regardless of their age



# Useful resources



- Understanding Benchmarking: RCN guidance for nursing staff working with children and young people. RCN (2014)
- Essence of Care 2010. DH (2010)
- Sharing the evidence: clinical practice benchmarking to improve continuously the quality of care. Ellis (2000)



- The commissioning and benchmark tool. NICE (2012)
- Achieving excellence: The quality delivery plan for NHS in Wales 2012-2016. Welsh Assembly Government (2012)