

# Bone Cancer Research Trust

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## Biospecimen collection

International Osteosarcoma Research Symposium

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CHARITABLE INCORPORATED ORGANISATION (CIO) NUMBER - 1159590

# About the Bone Cancer Research Trust

- In 2004, a group of families who had lost children and young people to primary bone cancer came together and by 2006 the Bone Cancer Research Trust had been registered as a charity
- Today, we are the leading charity dedicated to fighting primary bone cancer. Our mission is to save lives and improve outcomes through **research, information, awareness and support**
- We are small but impactful charity based in Leeds, West Yorkshire, funding pioneering research throughout the UK and supporting families across the globe
- In 2018 our annual income surpassed £1million for the first time and we committed over £950,000 to new research
- To date we have funded 70 pioneering research projects, 37 of these aimed specifically at osteosarcoma totalling £2,179,489



# Primary Bone Cancer Sample Collection

## Why are we so interested in this...

- Access to patient samples has been a significant issue for researchers, which has limited the success of research projects
- There are increasing numbers of projects which rely on access to patient samples for their success
- There has been a shift from small local projects, to national collaborative projects
- Bone sarcomas were included within the remit of the 100,000 Genomes project, however, centres were struggling to support this project
- We feel that improving access to patient samples is a fundamental step in supporting ongoing research and stimulating new research.
- **Our patients are passionate about this**

# Primary Bone Cancer Sample Collection

## How are we doing this

- BCRT undertook a 2 year project to understand the best way of supporting sample collection.
- Worked with centres to find out where the issues lie
- In 2017 we launched a new type of grant – **Infrastructure Grants**
- Funding can be used in a variety of ways – staff, consumables, equipment
- Focused on collecting samples for approved biological studies or research projects.
- Biobanking of samples is not the focus of this initiative, however, the grants do support this process where samples are not needed for active research
- Aimed at improving the quality of samples collected and to ensure transparency in sample sharing



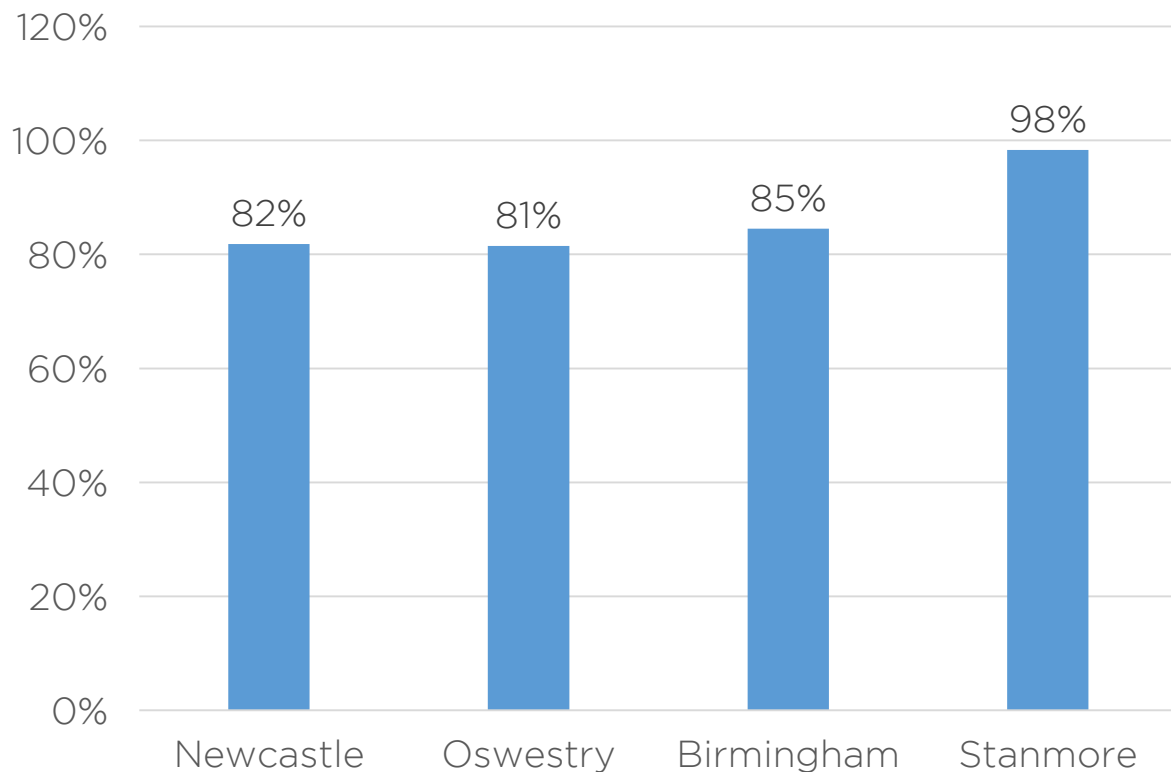
# Progress to date



- All 5 surgical centres in England have actively engaged in this process and have received funding
  - Our funding is supporting 8 members of staff, allowing dedicated time for sample collection
- The centres have come together to form a network – supported by BCRT
  - Regular status meetings are held to monitor progress, problem solve & share best practice
- 4 of the centres received funding in 2017 and have provided a progress report
  - Oxford received funding 6 months later and are yet to report progress
- Between the 4 centres, **12 research projects** have been supported during the reporting period

# Patients consented

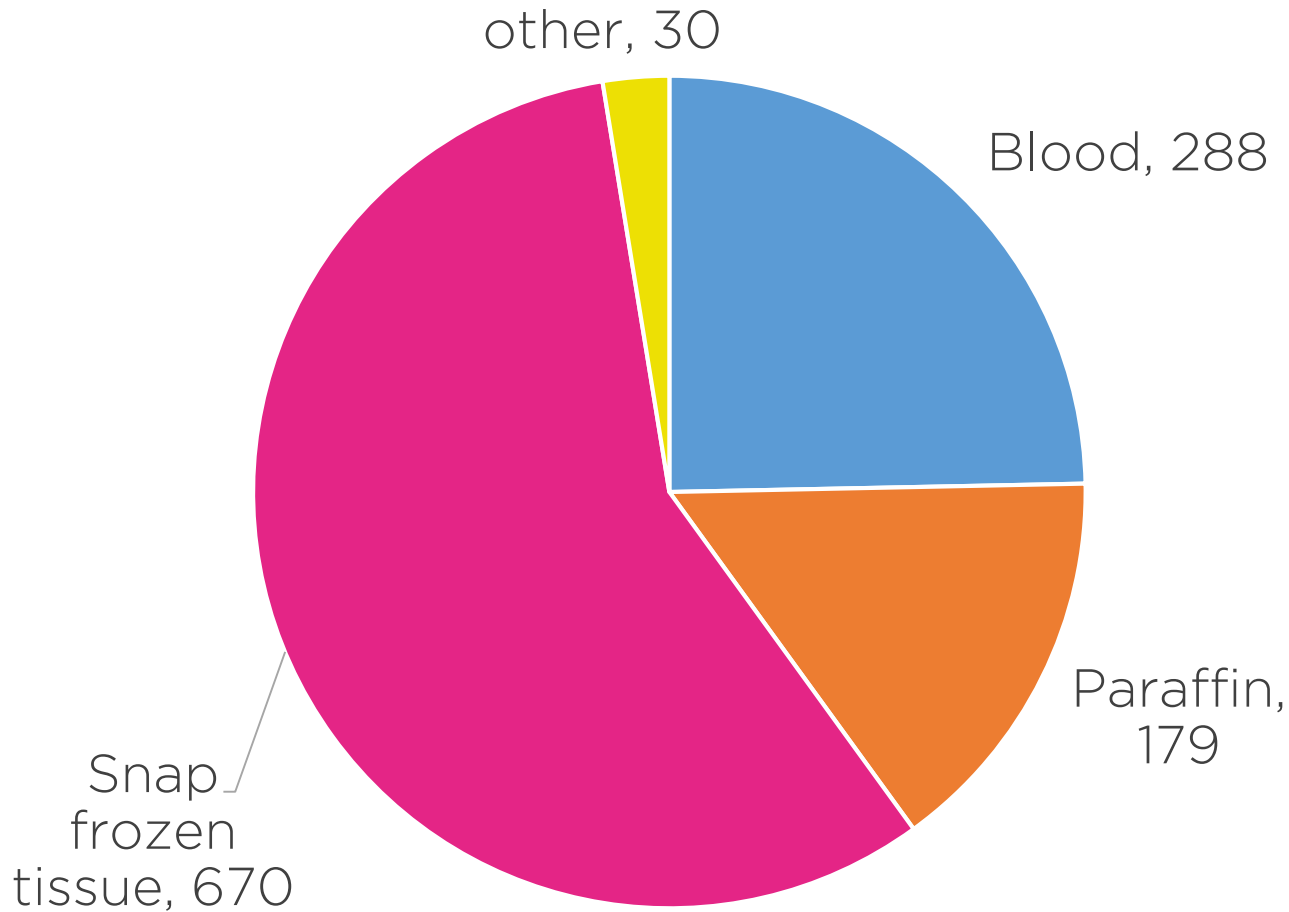
## % patients consented vs approached



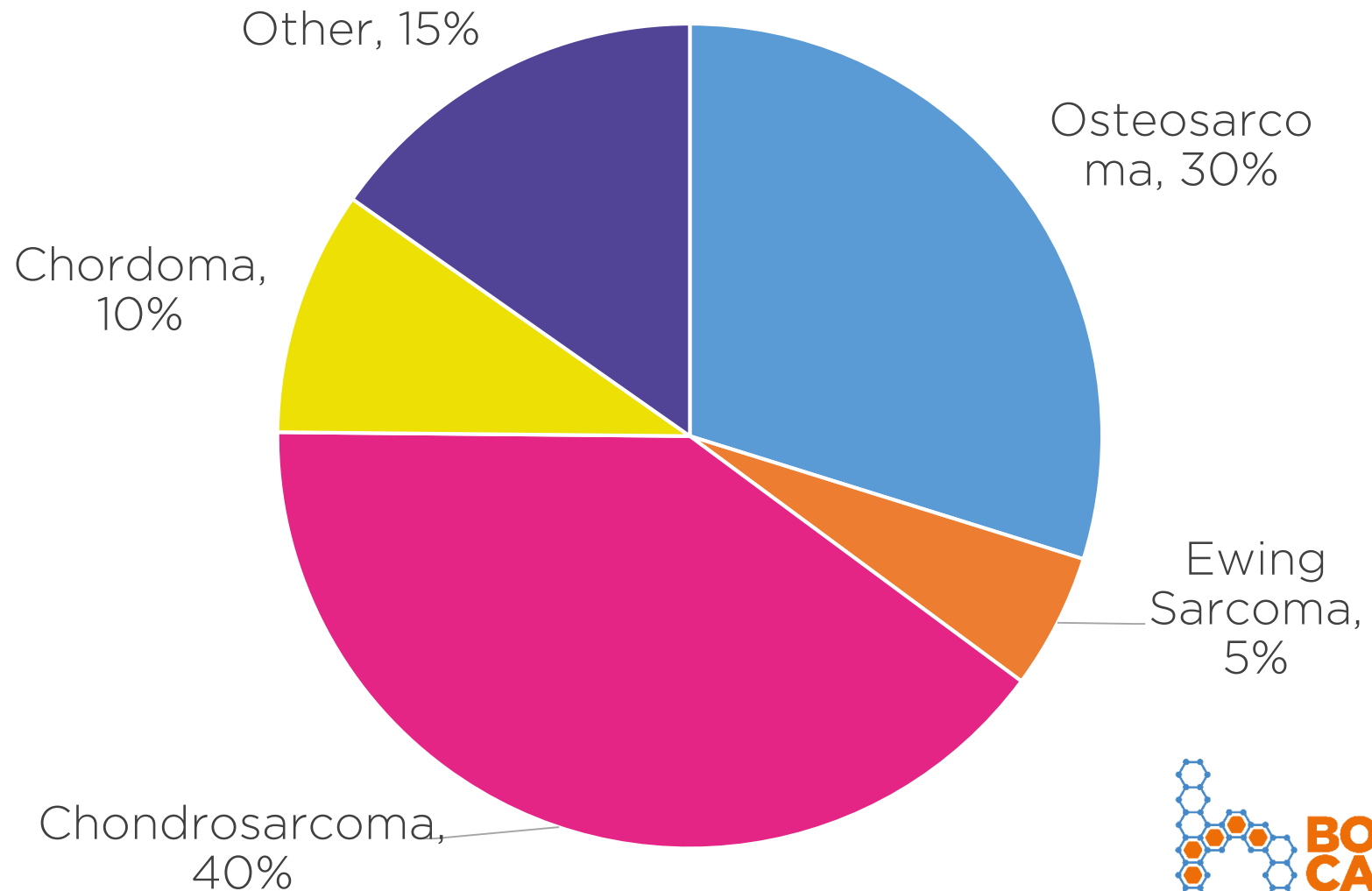
- During the reporting period there were **295** new cases of PBC
- Some Centres retrospectively consented patients
- A total of **231** patients gave consent for sample collection

# Number of samples collected

1167 samples were collected during the reporting period



# Samples by PBC type





# Challenges

- Pathology
  - Heavy demand on the pathologists
  - The pathology for the 5 Centres is being done currently by 3 pathology departments
- Biopsy
  - Move towards image guided biopsy
  - Sufficient material for research
- Identification
  - Patient identification – key step and still a challenge in certain Centres

# Thank you for your attention!

