

Tissue Donation

What the patient wants ...

... a personal view

Roger Wilson

Trustee – The Sarcoma Trust



A personal view

- My story
- Some reflections on big issues
- From the patient viewpoint
- Implications today
- Is there an elephant in the room ?

My story

- Diagnosed with a rare cancer in 1999
 - Surgery, recurrences in 2000, further surgery and chemotherapy, third recurrence 2007
- Approached to permit tissue from second surgery to be used in a study
- Have been a member of NCRI CLG since 2002 so have kept alongside the tissue debate
- Have followed progress of study

THE NEW YORK TIMES BESTSELLER

THE IMMORTAL LIFE OF HENRIETTA LACKS

Rebecca Skloot



In 1951, a young woman from Baltimore died of cancer. Her death changed medical science for ever.

Big Issues

Big issues

- Patient consent
 - informed/documentated etc
- Patient identification
- Commercialising tissue
- Altruism versus profit
 - and whose profit?
- Exploitation beyond perceived initial use
- What does the family know ?



Big issues

- UK history of Alder Hey and Bristol
- Human Tissue Act
 - Recognises the big issues
- Regulator change proposed
 - Transfer to ‘appropriate bodies’ by 2013
 - No suggestion of any other legislative change

Starting from the patient viewpoint

- Altruism
- Personal
- Family

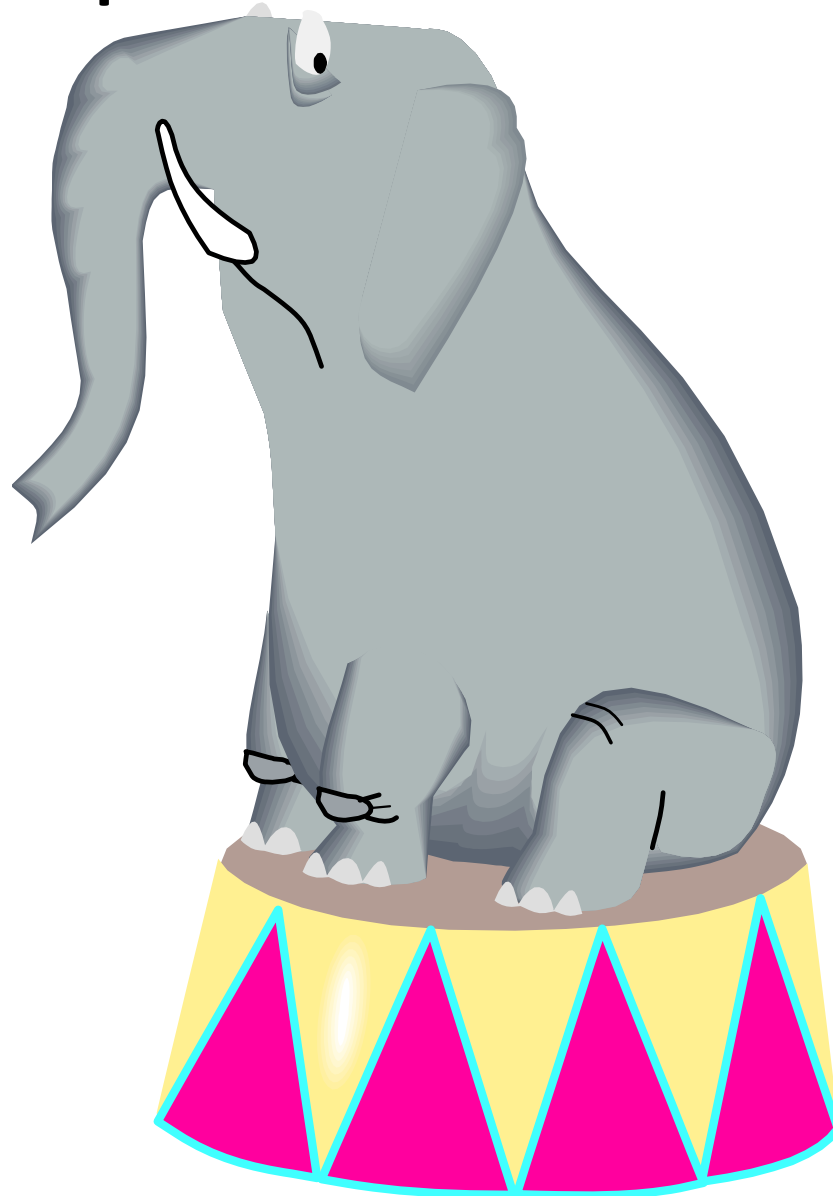
Implications

- The nature of informed consent
 - Ethics is as much about what ‘might happen’ as what ‘will happen’ to tissue
 - Time to consider, consult with family
 - Expertise available to answer questions
- Data security
 - Cannot afford to have it compromised
 - If a financial company can lose 40,000 account records ... (fine £2.5m)

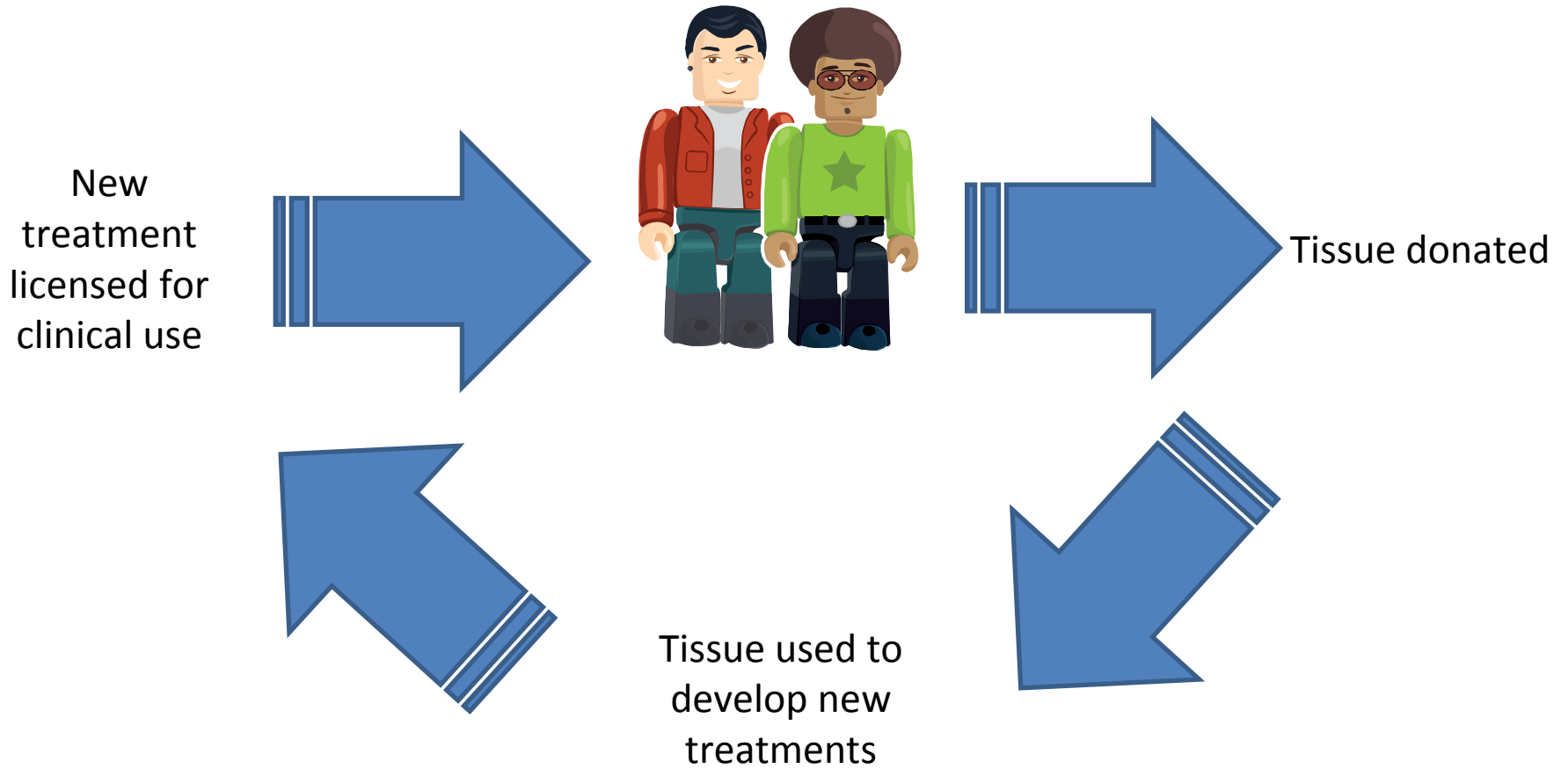
Implications

- Genetic profiling
 - Personal information
 - May have value in treatment as well
 - Family information
 - Could be restrictive in future
- Genetic exploitation
 - Cloning
 - What else ... ?

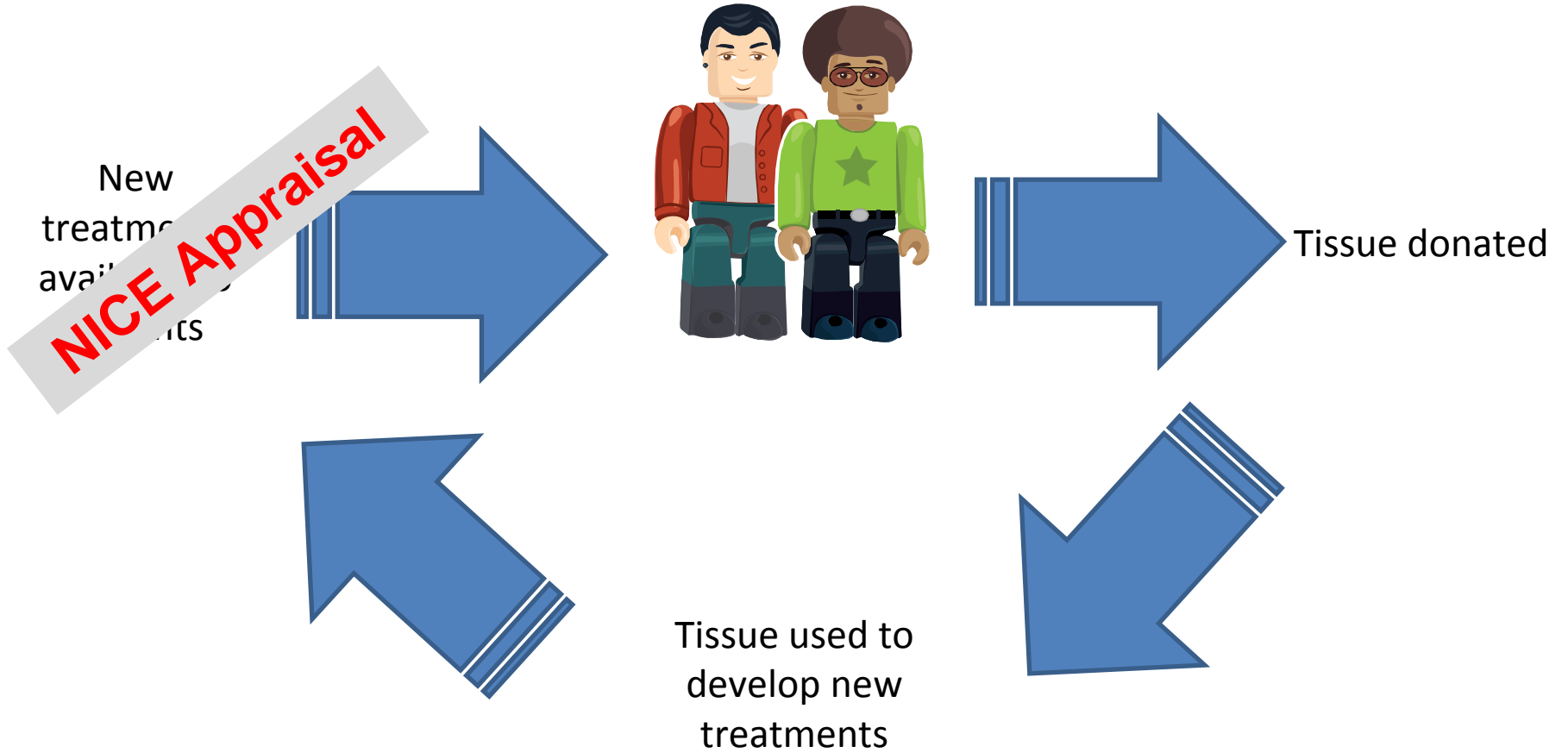
The elephant in the room ?



The elephant in the room ?

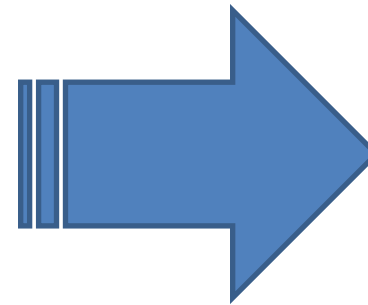


The elephant in the room ?

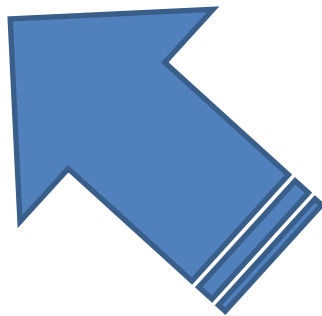


The elephant in the room ?

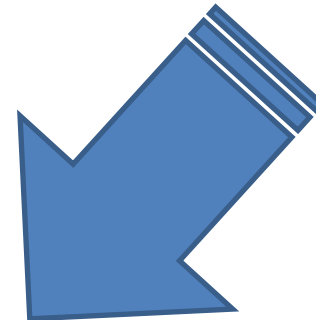
NICE – “not recommended for use in the NHS.”



Tissue donated



Tissue used to
develop new
treatments



A final thought

- How do we reconcile patient altruism (donation of a precious resource) and NHS denial of treatment (NICE/Health Technology Assessment)
- What if patients became militant about denial of treatment and create a (moral?) demand in return for their tissue donation ?



Roger Wilson

Trustee – The Sarcoma Trust

roger_wilson@sarcomatrust.org.uk

