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21st Annual Conference *of the* **National HIV Nurses Association (NHIVNA)**

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21st

Annual Conference of the National HIV Nurses Association (NHIVNA)



The AIDS Era: an oral history of UK healthcare workers

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Declaration of interests relating to this presentation

- **Nothing to declare for either speaker**

The AIDS Era; an oral history of UK healthcare workers



The Project Team

Jane Bruton, Sian Edwards and Nicky Perry (manager)

The Interviewers

Wendy Rickard, Debra Hearne, Fiona Clampin, Sian Edwards, Jane Bruton

The Volunteers

Claire Bradbury, Martin Jones, Paul Mason , Julia Parr, Chris Harrington, George Leach, Barbara Hayman

The Advisory Group

Prof. Brian Gazzard (HIV Consultant), Dr. Rob Perks (British Library) Prof. Alistair Thomson (Oral Historian)

National HIV Nurses Association (NHIVNA), British HIV Association (BHIVA), Children's HIV Association (CHIVA), National AIDS Trust (NAT)

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What is Oral history?

- In-depth, extensive, unstructured, account often using a 'life history' approach
- An opportunity for those 'hidden from history' the 'silent voices' to be heard
- A source of new perspectives - that may challenge/add to the traditional view of the past and formal historical accounts
- Contrast to guided interviews, where data collected is interpreted by someone else. Anonymous. Source data destroyed once data obtained.
- Preservation for use now and by future generations
- The voice will be preserved to tell the story

25 male
36 female

38 South East (incl London)
9 North/Midlands/East
3 South and South West
9 Scotland
2 Wales

61 life history interviews

in The British Library
Sound Archive

24 Nurses/Midwife
24 Doctors
10 Allied health care
3 Other

In patient, out patient, paediatrics, family
care, mental health, haemophilia,
education, palliative care, drug use,
pregnancy, community care & research

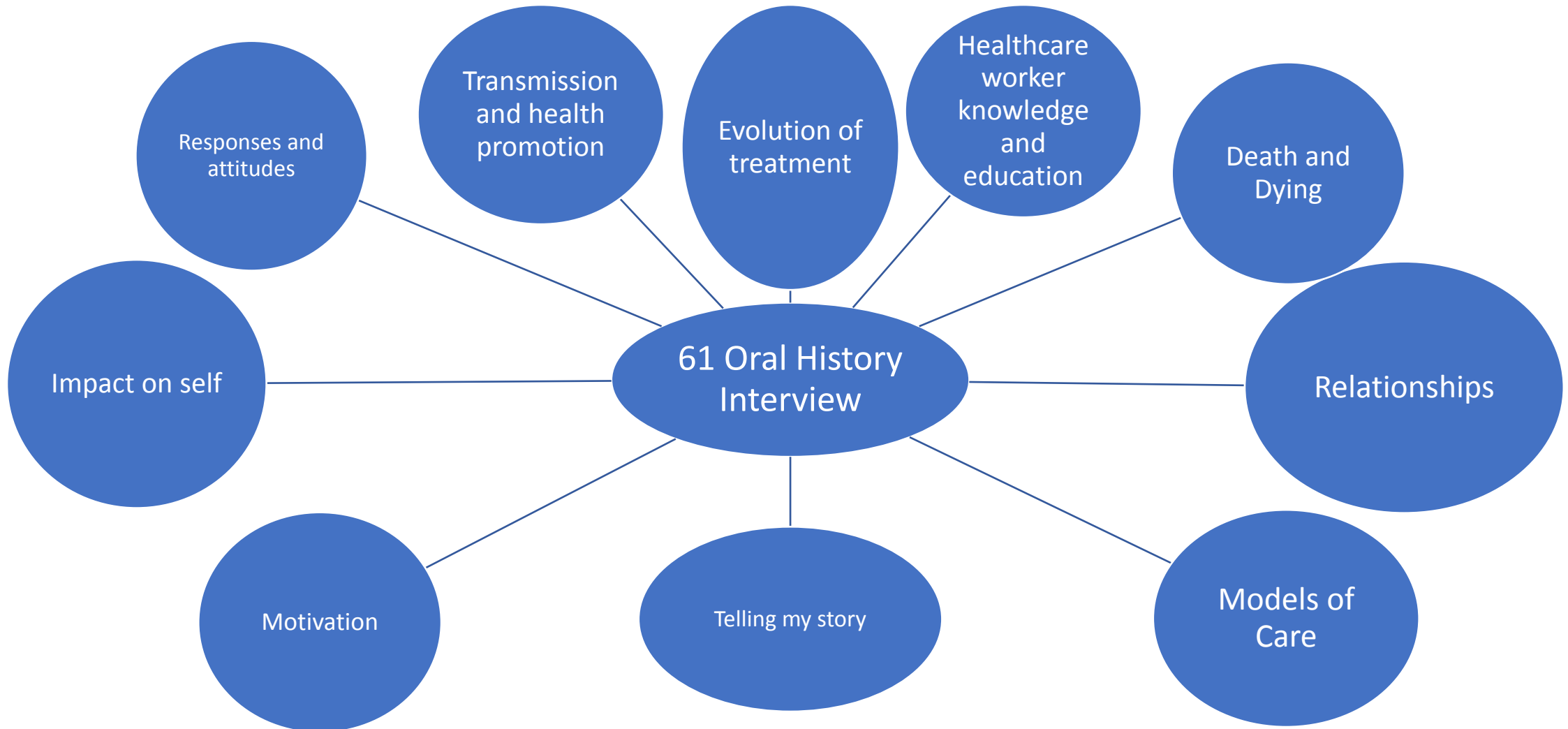
...I think one of the attractions of the oral history project that we're doing is that you will also hear from the north of England, you will also hear in great detail from nurses, from social workers, from other people who were involved in this epidemic, as well as the sort of, rather top-down approach that, you know, the professor of HIV medicine might have. And so I think for the future it's very important
[Brian G doctor]

...a lot of the people who were originally affected by HIV were very marginalised groups whose voices weren't heard, whether that was gay men or, people with drug problems etcetera. It's important those voices are heard, even if it's second-hand through my experience working in Edinburgh in the Eighties and Nineties [James E nurse]

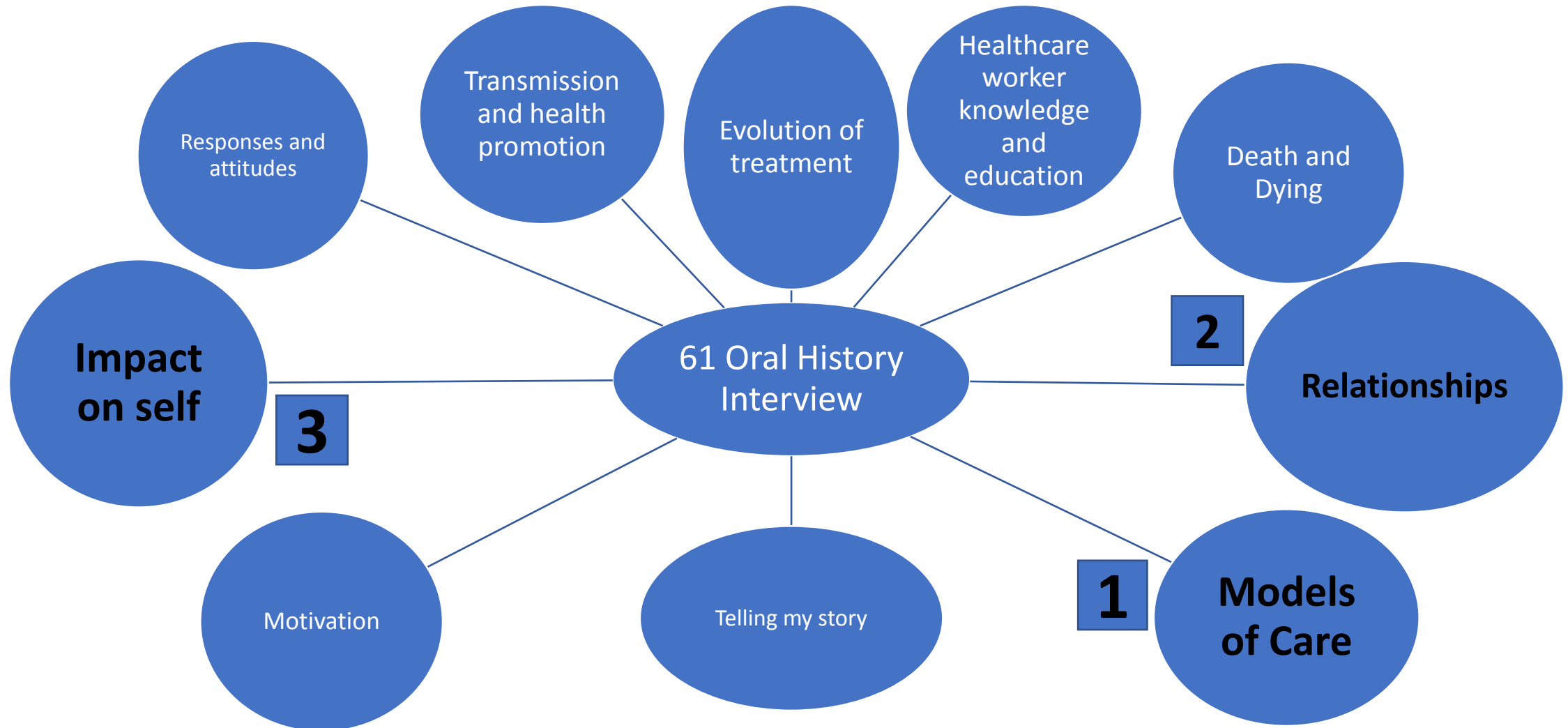
I wanted to do it very much indeed, because Lighthouse is so important, you know, it's important in the history of healthcare, caring for people. It was something completely new, completely innovative, unique...I am a great believer in providing information for posterity and I have got a four-year-old great-granddaughter and it's nice, comforting to think that after, long after I'm dead, if she's interested she can trot along to the British Library and hear her great-grandfather's voice and that's quite comforting [Chris B volunteer]



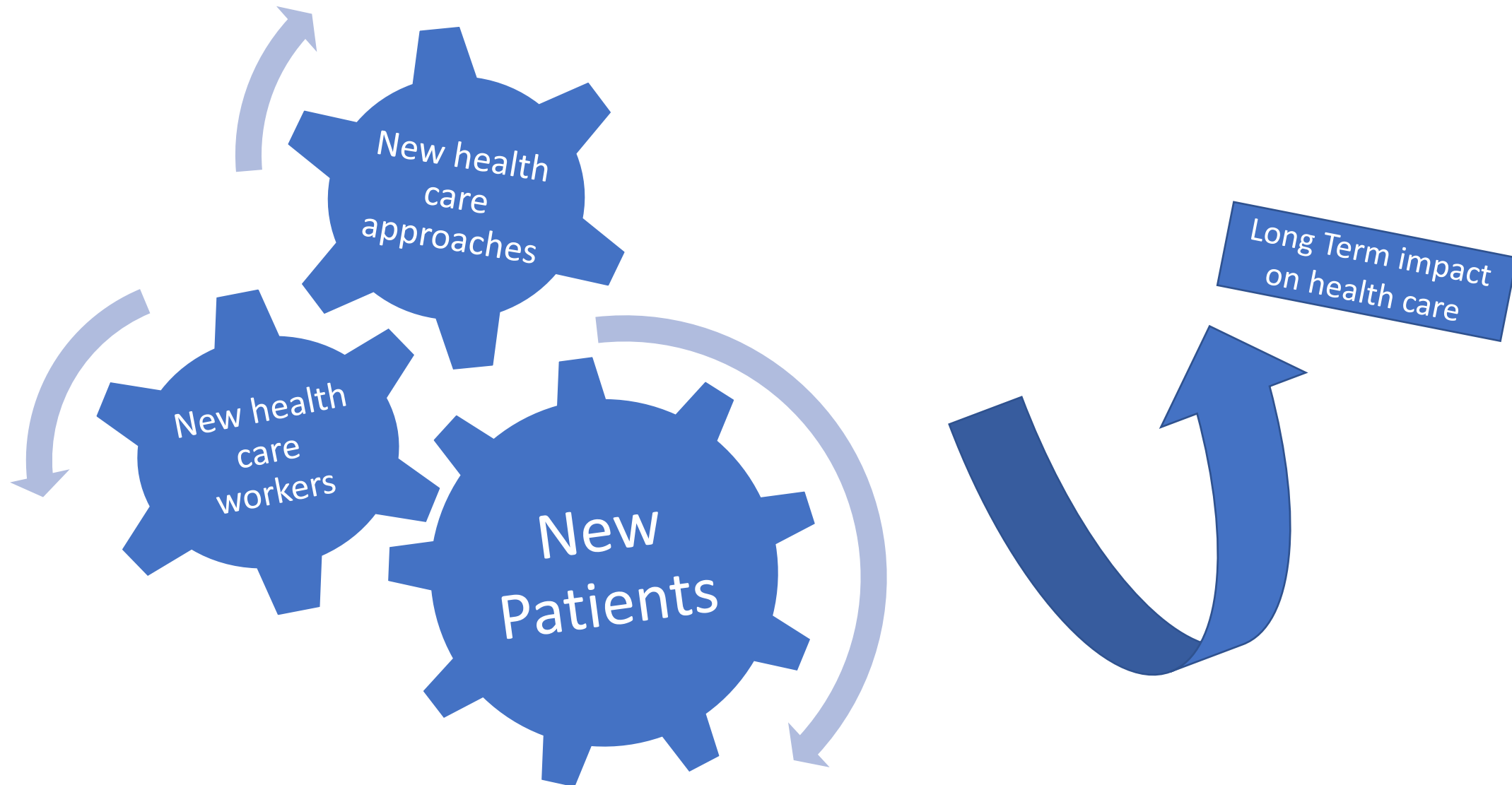
The Emerging themes



The Emerging themes



Changing models of health care



Changing models of health care

New patients

Eileen, Nurse



young, previously healthy, activists, informed
stigmatised, alone, rejected
chaotic, multiple social needs

Lorna, Nurse



children, families, diverse cultures, friends, colleagues
bereaved, dying

New approaches

Jane, Nurse



new, innovative, patient centred, partnerships,
multi-disciplinary,
relaxed professional boundaries/ rules and regulation

Candy, Nurse



New healthcare workers

Geraldine, Nurse



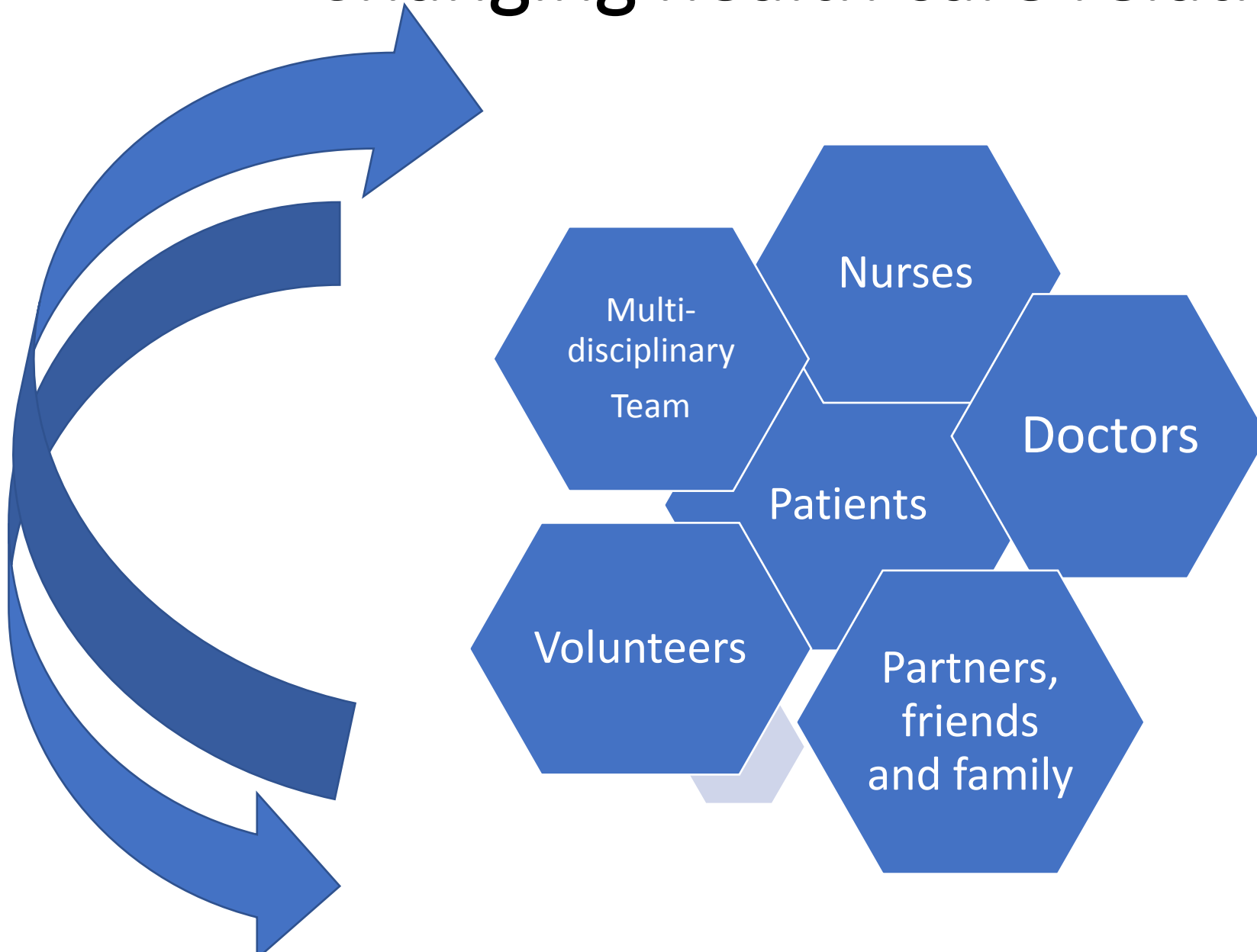
responsive, gay, activists, HIV positive, invested,
committed,
friends, patients
volunteers

Simon, Doctor



Long Term impact
on health care

Changing health care relationships



Changing health care relationships

Relationships between HCWs

Flattened hierarchy
doctors and nurses ->
multidisciplinary team +++

Nicky P
Nurse



introduction of formal support
emphasis on informal support ->
intense personal relationships
between staff
colleagues ->patients

Jim K
Psychologist



Sheila M
Nurse



Relationships between patients and HCWs

activism
partnerships
patient centred care

fracturing of traditional family
-> care and support from healthcare
workers/volunteers/other patients

Challenging rules and regulations
Relaxed professional boundaries
Patients -> friends
Friends -> patients

Different demographic in Scotland
Very different narrative of relationships

Impact on self

Negative

Stephen H, Nurse



Relationships

intense support
fun laughter parties
friendships sex

academic,
intellectual
fascination
excitement

compassion
care
humanity
The extra mile

new perspective
improved self
worth
empathy
communication

immersion
all encompassing
passion
privilege

Worn out
Burn out
Depression

Blurred
professional
boundaries

Close
personal
identification

David O, Nurse



Jane S, Nurse



Positive

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Website

<https://www.healthcareworkersinhiv.org.uk/wp-login.php?loggedout=true>



Any other
thoughts on
how this
project could
be used?