Public Engagement and SHIP

Sarah Cunningham-Burley

Mhairi Aitken

Claudia Pagliari

SHIP
Scottish Health Informatics Programme

wellcome trust
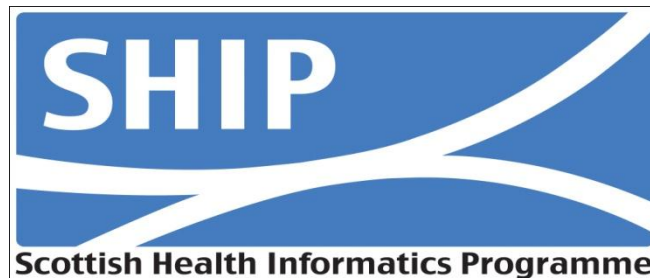
Outline

- Public Engagement - what is it and why promote it?
- Public attitudes to data linkage/data sharing – findings from SHIP and other studies
- Public engagement for SHIP – what next

Public Engagement - what is it?

- Trend towards increased public participation in policy areas
- Such involvement takes many different forms; imprecisely defined
- Instability of terms, concepts, meanings and goals
- Competing claims/demands associated with PE - its under-specification may be functional to policy makers and others

Public Engagement - why do it?

- Decision making should take account of public attitudes
- Public engagement can revitalise democracy
- Public engagement can strengthen democratic institutions - better public policy
- Extends what constitutes expertise on an issue and allows mutual learning

Types of engagement (Aitken 2010)

	Purpose	Desired Outcome	Potential Methods
Awareness Raising	Information provision and public education.	Greater public acceptance or legitimacy for policy/project.	Media campaign. Public exhibition/ presentations. Leaflets.
Consultation	To gain insight into public opinion/views.	Creation of appropriate/socially acceptable policy/project.	Surveys. Focus groups.
Empowerment	To work with the public enabling them to play key roles in decision-making.	Greater social capital. Capacity building. Enhanced democracy.	User panels. Citizens' juries.

What are your views?

- What are the roles of public engagement within SHIP?

- What is the role of researchers in SHIP's public engagement

- What might researchers/stakeholders learn from public engagement and how might this influence practice?

Evidence for public acceptability from diverse studies

- Awareness low but publics seem to recognise that data linkage is important for research and service planning
- A number of studies have indicated general public support for uses of (health) data for (health) research
- Some assume data linkage/sharing is already routine
- General acceptance of public benefit argument, especially for health research
- Varying degrees of trust in different sectors, institutions, individuals

Evidence for public concerns

- Consent/Control
- Confidentiality, privacy and anonymisation
- Access, particularly commercial access
- Trust
- Purposes

General Responses to Data-Sharing (SHIP)

FOR HEALTHCARE

FOR RESEARCH

Doesn't this happen already?

If it benefits the patient – of course you should share my information

Who would access this?

For what purpose?

How is it controlled? Who is accountable?

Will this be of benefit to patients and/or wider society?

How secure is it?

Authorisation

"it's taking any kind of power away from the individual"

- How do you ensure that public interests are reflected?

- How do authorisers know what an individual would/would not consent to?

- Authorising bodies will operate with a bias in favour of allowing research to go ahead

- Will they be influenced by commercial/political interests?

Control

- Participants often stated that it was crucial that individuals had control over how their data was used but had different understandings of what control would mean

- Trust in the individual/organisation seemed to mean less need for explicit forms of individual control

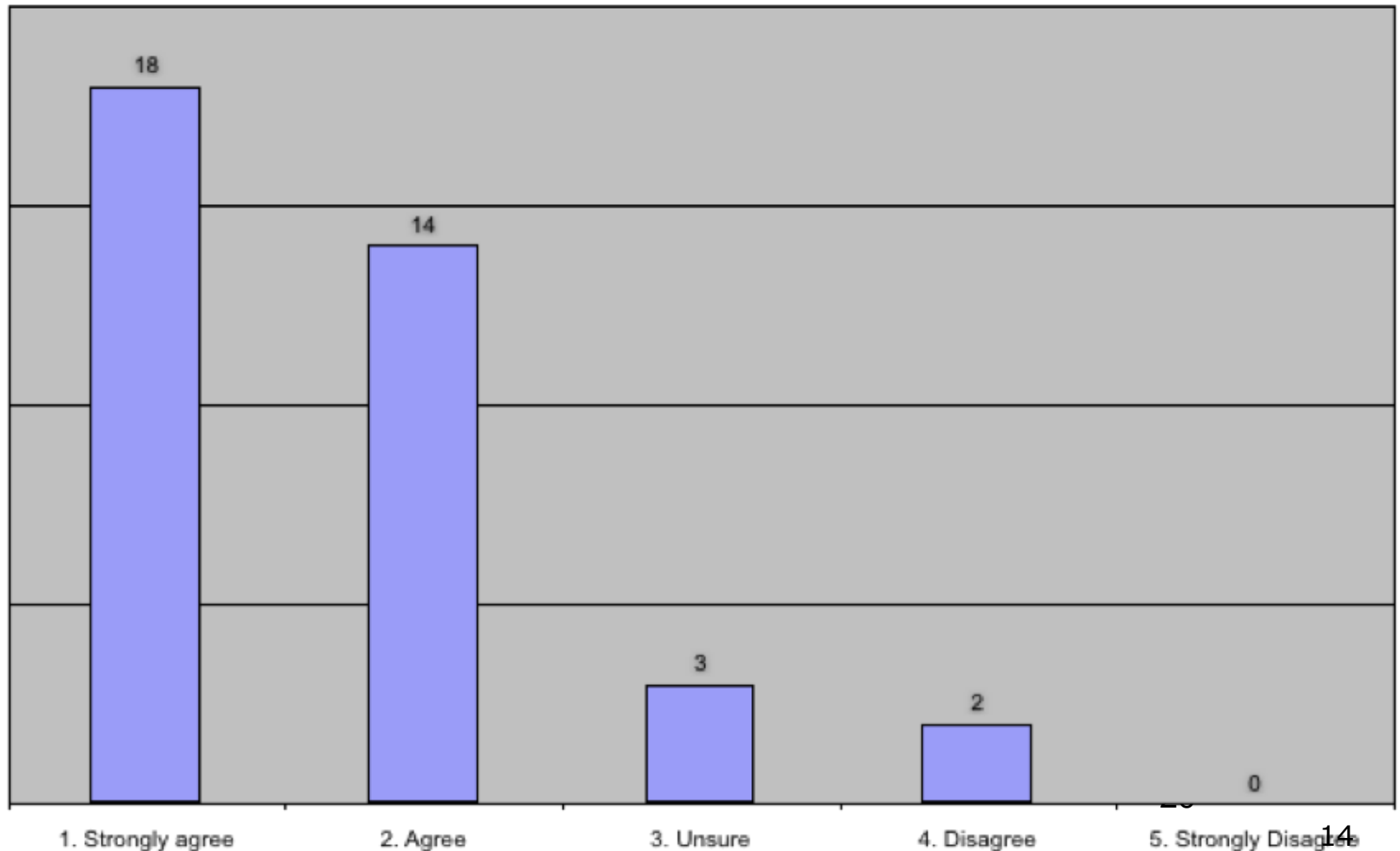# How might SHIP respond to public views?

- The need for a sense of control?

- Involvement in authorisation processes?

- Responding to trust

- Access arrangements and benefit sharing
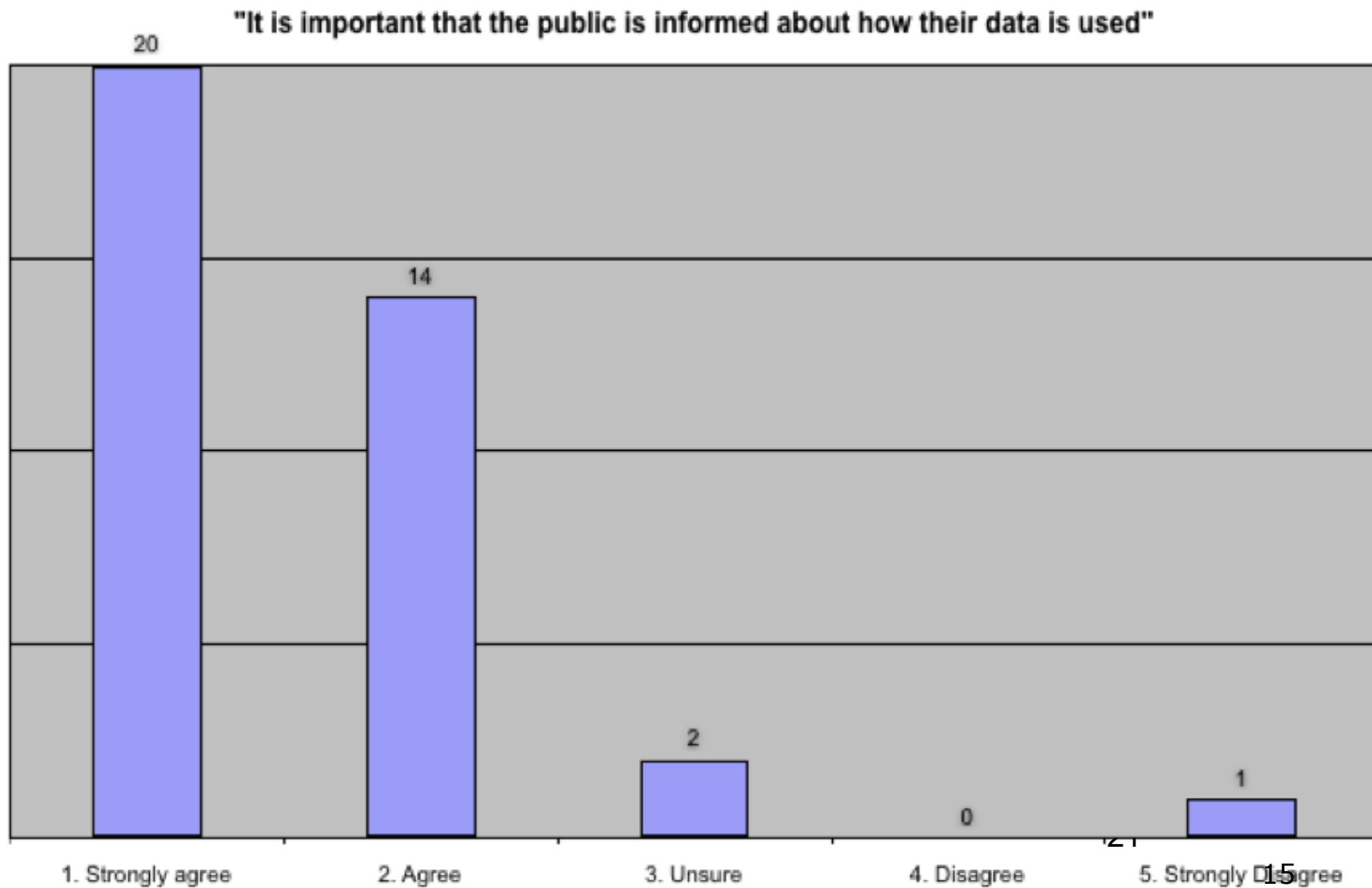
Evidence supporting public involvement

- Most public engagement activities are well received by participants
- Participants are keen to learn and to explore theirs and others' opinions
- Participants also think the public should be more involved in decision making
- Participants want and expect to be given information about how their data are used

13

Public Engagement in Data Linkage/Data Sharing

"The public should play a role in setting research priorities"

Public Attitudes to Data Linkage and Data Sharing

"It is important that the public is informed about how their data is used"

	1. Strongly agree	2. Agree	3. Unsure	4. Disagree	5. Strongly Disagree
Count	20	14	2	0	1

Developing a PE strategy

○ Awareness raising
  - Concerted effort to generate greater knowledge of health related data-linkage, its purposes, challenges and governance

○ Consultation
  - Where further insight into public attitudes is required (e.g. for new forms of linkage; new purposes) or on-going (e.g. through a public consultative panel)

○ Empowerment
  - Bringing the public into decision-making (e.g. through representation on key committees; citizens' juries)

Where next for PE and SHIP?

- What else can we do within SHIP?
- How can we ensure greater transparency – the feedback loop?
- Making the most of social media?
- The next steps – shorter and longer term