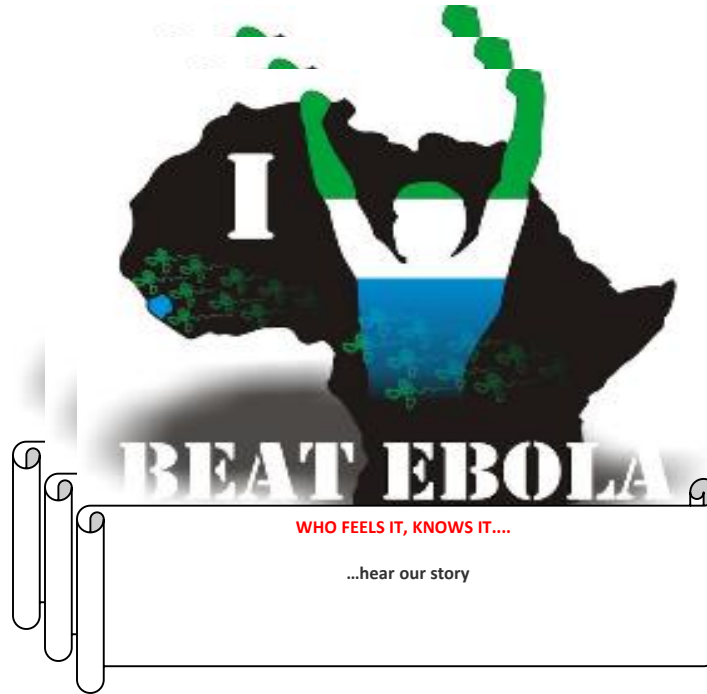
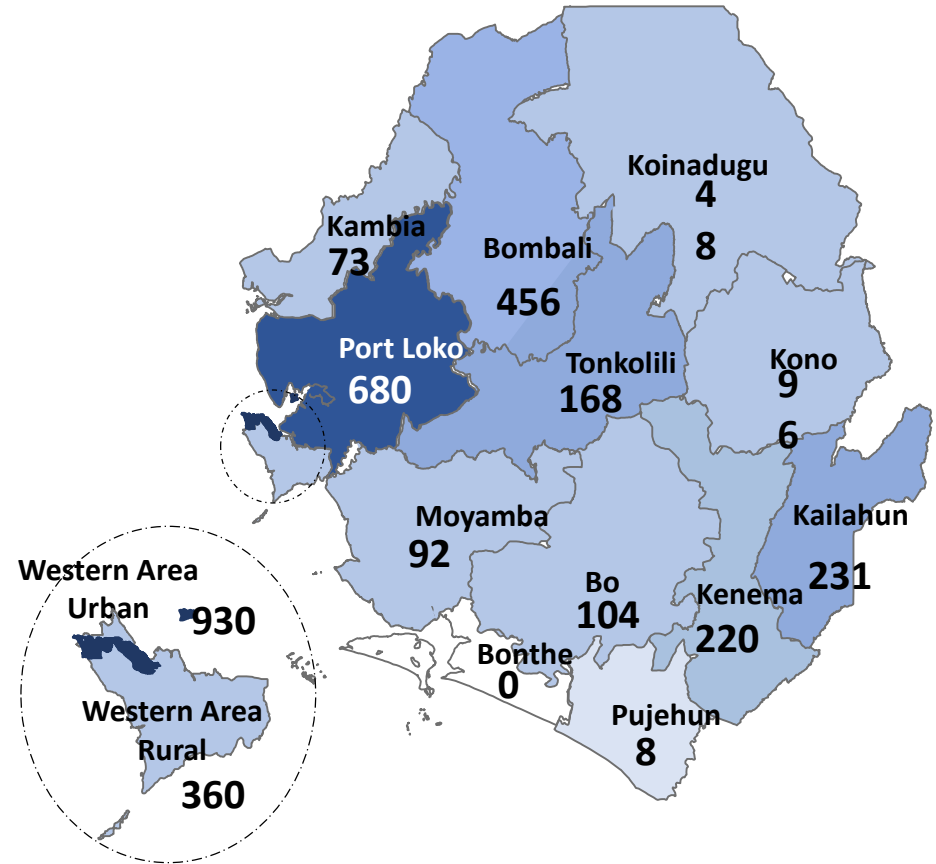


SIERRA LEONE ASSOCIATION OF EBOLA SURVIVORS



Brief History of SLAES

- Founded 7th January, 2015
- 4052 survivors discharged
- 3,466 survivors registered
- 13 Districts in Sierra Leone (highest concentration of survivors in Sierra Leone are in Western Area and Port Loko)



Outline

Introduction to the "Perceptions" study

Key findings from interviews with survivors

Questions and comments

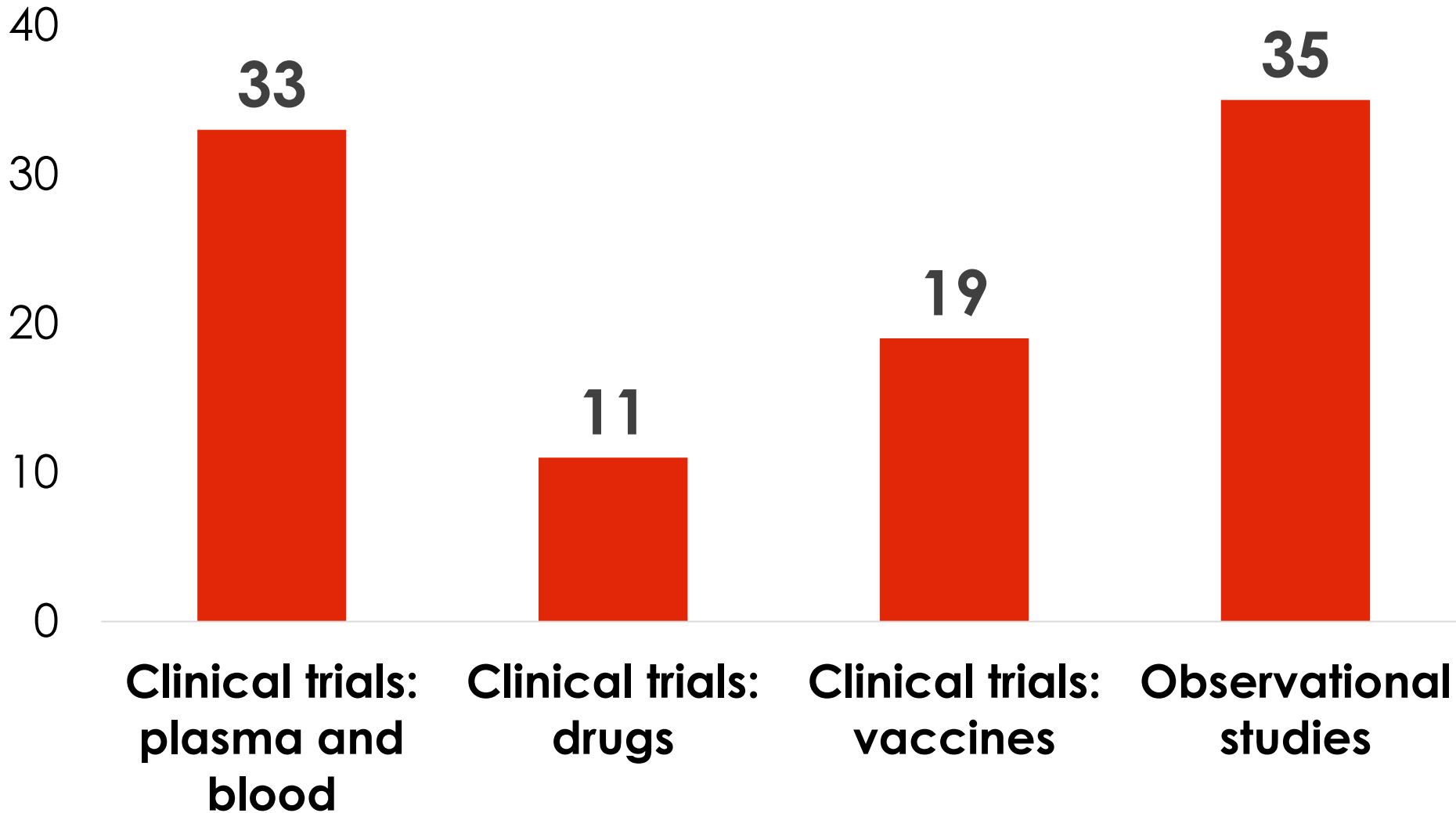
Discussion – dissemination plans

Perceptions and moral experiences of research conducted during the West Africa Ebola outbreak

Goals:

- To better understand practical and ethical challenges of research conducted during the epidemic.
- To support the development of recommendations for the ethical conduct of research in public health emergencies.

Types of studies the 70 participants were involved in:



How did people decide whether or not to participate in research?

Diversity!

How did people decide whether or not to participate in research?

Fears about participating

- **Stigma**
- **Effects of experimental treatments**
- **Mistrust of medical and research teams**

How did people decide whether or not to participate in research?

Sharing the decision

- **Consultation sometimes impossible**
- **Different attitudes towards consultation**

How did people decide whether or not to participate in research?

Motivations for participating

- **Surviving or regaining health**
- **Helping others survive or regain health**
- **Finding a cure or vaccine**
- **Leading by example**
- **Trusting in God or destiny**

How did people decide whether or not to participate in research?

Motivations for participating

- **Wanting to help others**

How did people decide what to believe, and who to trust?

Not easy: Contradictory information

How did people decide what to believe, and who to trust?

Trust in certain groups

- **Healthcare providers and the healthcare system**
- **Survivors' Associations**
- **Personal and community ties**

How did people decide what to believe, and who to trust?

Looking for evidence

- **Observing what researchers do, not what they say**
- **Observing what happens to others**

How did participants experience their participation in the research study?

What was appreciated:

- **Free medical care**
- **Quality of care**
- **Screening tests**
- **Communication with the research team**

How did participants experience their participation in the research study?

What was difficult or felt wrong:

- **Re-living painful memories**
- **Stigmatization**
- **Lack of communication between team and participants**
- **Side effects**
- **Painful procedures**
- **Feeling at risk**
- **Lack of confidentiality**

How did participants experience their participation in the research study?

What was difficult or felt wrong:

- **Lack of follow-up!**
- **Compensation not delivered**

Were participants able to give free and informed consent?

Informed consent requires knowing about:

- **Freedom to refuse**
- **Research vs healthcare**
- **Uncertain efficacy of experimental treatments**
- **Potential risks**

Were participants able to give free and informed consent?

Freedom to consent or refuse

Thank you!

→ We have questions for you!

Next steps

- Do these results seem true to your experiences?
- Which findings are most important to you?
- Do you think there would be some value in developing a training for research participants?
- What measures are in place to address the growing healthcare concerns of Ebola survivors in Sierra Leone?
- What are you doing to ensure inclusion of EVD Survivors in decisions that affect them?

Next steps

- **Are there any plans for building the capacity of Ebola Survivors in terms of conducting research?**