

The Importance of Participation – Rethinking Clinical Trials

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**Direct to Consumer Recruiting for
Clinical Trials**

The Love Avon Army of Women,

a program of the

Dr. Susan Love Research Foundation

Dr Susan Love MD MBA

July 7, 2010

Our Mission

The Dr. Susan Love Research Foundation (DSLRF) is working to eradicate breast cancer and improve the quality of women's health through innovative research, education and advocacy.

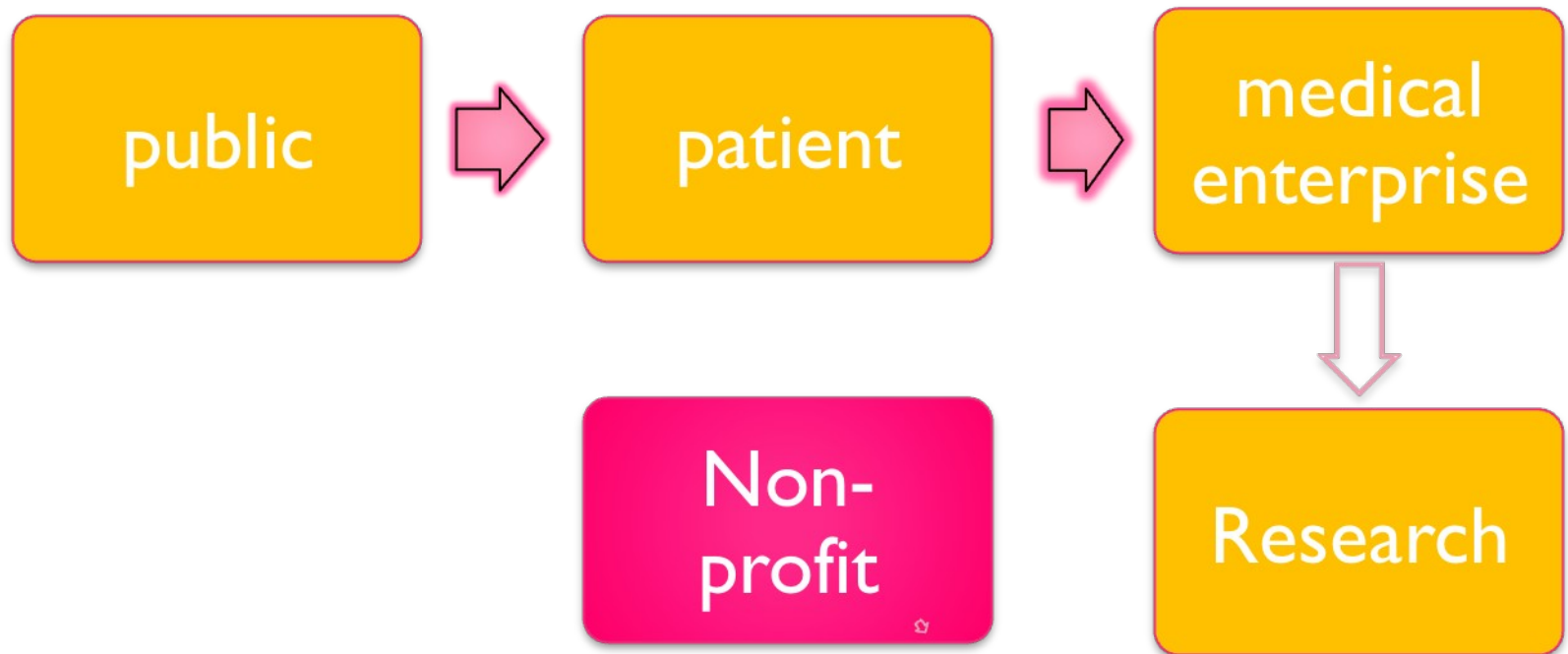
Our goal is to identify the barriers to research, to explore new approaches and create new solutions.

We are working to move breast cancer BEYOND A CURE through innovation and collaboration.

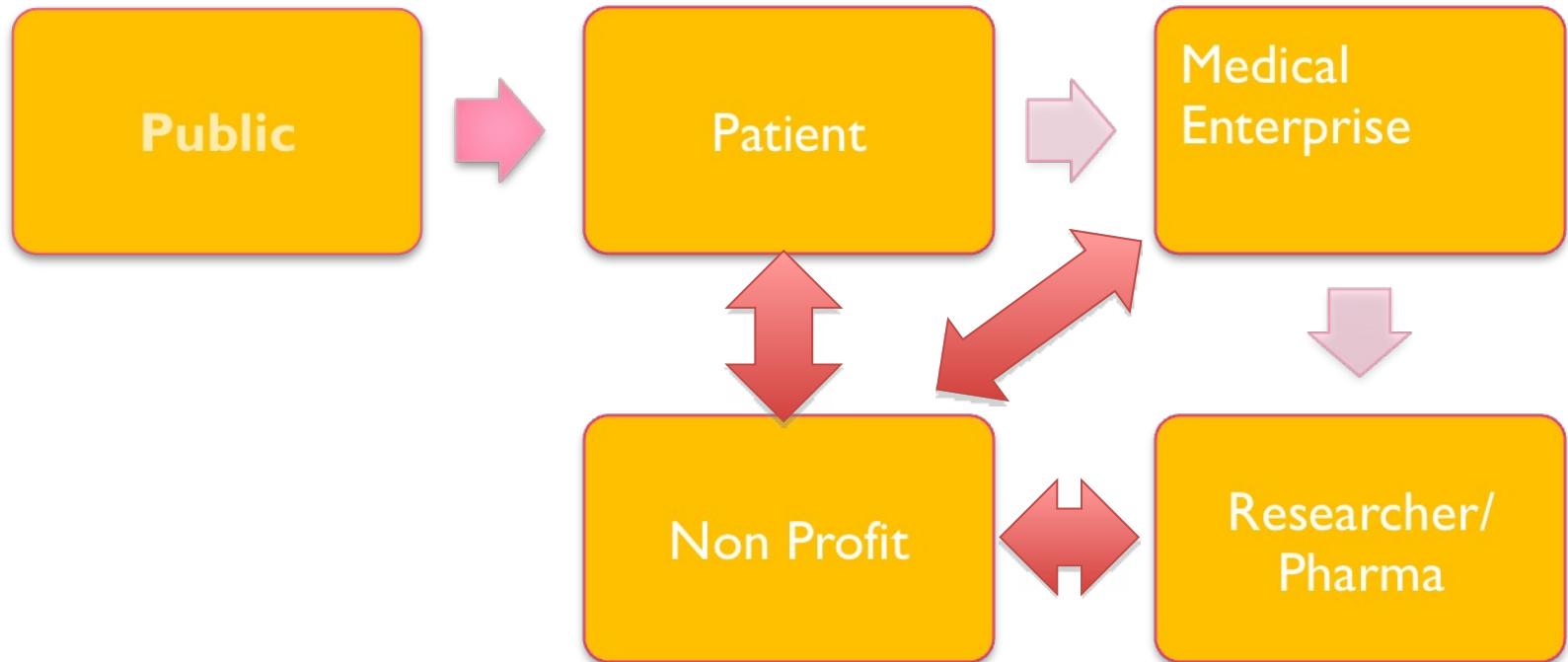
Common goals

- Goal:
 - To accelerate research that will address clinical problems.
- Background:
 - Old model: investigator initiated research.
 - Alternative model: non-profit initiated/facilitated research.
- Problem:
 - How to accelerate/initiate/facilitate research
 - Accessible bio-specimens
 - Accessible data
 - *Accessible clinical trial participants*
 - *Chronic diseases*
 - *Acute diseases*

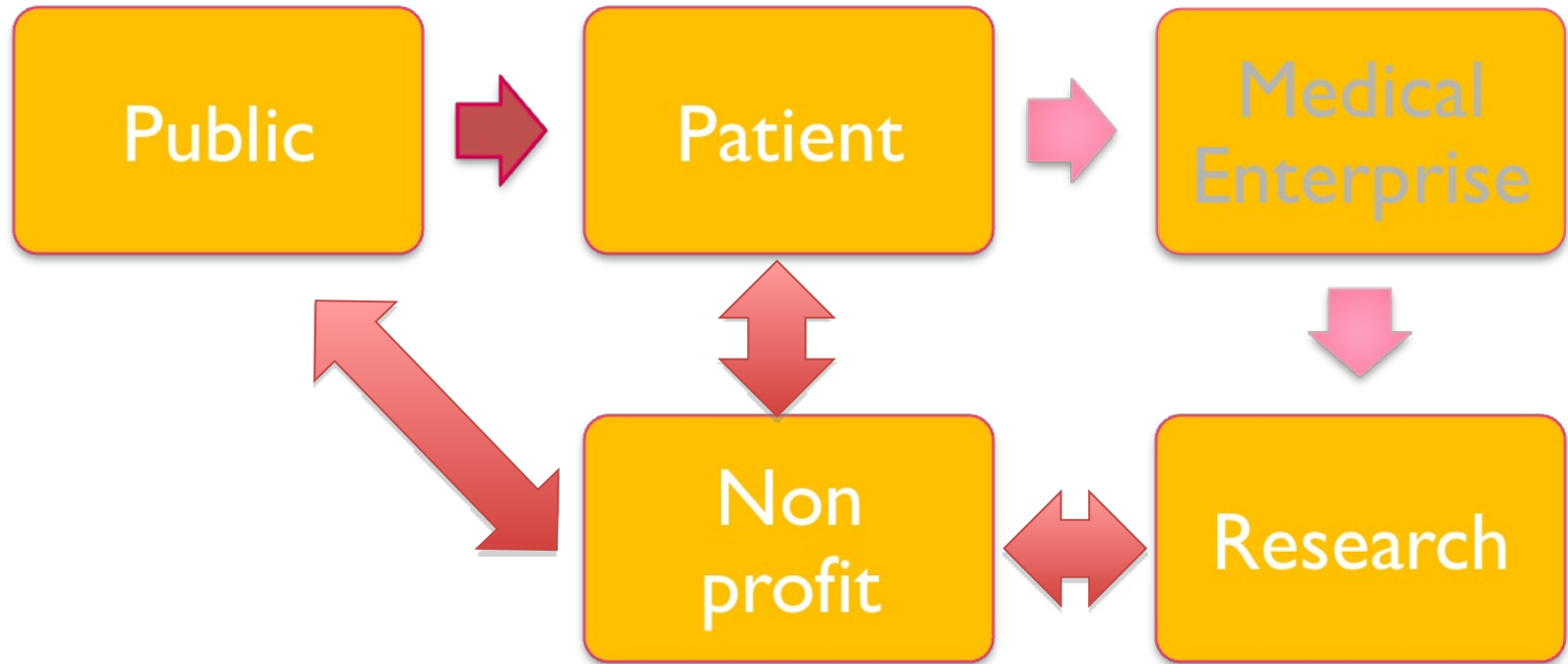
Problem



Disease Registry Bio-specimen Model



Direct with the Public Model



Solutions

Registry

- Specific recruitment
 - Currently recognized risk factors
 - **People with disease**
- Database for matching
 - Needs to be kept current
 - Limited to what is known
- Biobank
 - Technology of today
- Limitations
 - Expensive
 - Lot of work
 - May preclude discovering new information
- Benefits
 - ownership

Open Database

- Open recruitment
 - Willing to consider participating in research
 - **Healthy, predisease, disease**
- Broadcast email list
 - Participants self select
 - Adaptable to new hypothesis
- Just in time tissue and fluid collection
 - No storage
 - Adaptable to new technologies
- Limitations
 - No ownership
- Benefits
 - Less expensive
 - Can accommodate rare and common diseases

Love/Avon Army of Women

- Funded by a grant from the Avon Foundation.
- Encourage women to take the next step in breast cancer advocacy and participate in research.
- Get women invested in the concept of research to find the answers.
- Forge a partnership between women and researchers to end breast cancer.
- Increase the amount of research focused on the cause and prevention of breast cancer.
- Accelerate research by accessing a pool of ready volunteers.
- Encourage researchers to study clinically important questions.

Love/Avon Army of Women: How it Works

- Members
 - Women sign up online (www.armyofwomen.org) to receive email announcements of available studies.
 - If they are fit and are interested they RSVP and go through online screening.
 - They are passed on to the researchers.
- Researchers
 - Submit their studies online for approval by the Scientific Advisory Committee.
 - Obtain IRB approval for online recruiting.

Love Avon Army of Women

- Over **335,000** women recruited, **80%** healthy, **20%** survivors
- **31** studies launched, **16** studies closed, **6** studies increased recruitment due to success
- Many studies reach full recruitment within a week
- An active and growing Scientific Advisory Committee of **20** members
- A successful Foot Soldier Program with over **800** members
- Regular PR and blog mentions, including **Time Magazine, Glamour, Today Show** and much more.