

# **Boldly Going To New Horizons: Engaging the Community in Biomedical Research and Precision Medicine**



*Peter Shipman, MLIS*  
*Gail Kouame, MLIS*



# Consumer health

- MedlinePlus resonates with public
- Motivated consumers use PubMed
- Low interest in ClinicalTrials.gov
- NIH's *All of Us* unknown to consumers



# Henrietta Lacks

- Book by Rebecca Skloot and subsequent film
- Skloot and Lacks family come to Augusta during 2018 Black History Month – program well received
- Context – distrust of underrepresented groups in participating in clinical research



AUGUSTA UNIVERSITY

Robert B. Greenblatt, M.D.  
Library

# Precision medicine

- Precision Medicine Initiative, 2015
- Prevention and treatment approach that accounts for individual variability
- Computing technology, molecular biology, genomics, and bioinformatics converge
- Environment, behavioral, genomic factors
- Individualized approach to care
- Better assessment of disease risk



# How to publicize All of Us

- All of Us precision medicine initiative is inspiring
  - Interested in enrolling underrepresented groups
- Lacks story is inspiring
- MedlinePlus is popular
- Clinical trials research is not interesting

Three themes: Consumer health > Clinical Trials > All of Us



# Health improves with participation in research

- Demonstrate MedlinePlus as authoritative source
- Postulate how MedlinePlus information is derived from clinical research

- Dulaglutide (Trulicity), taken weekly
- Exenatide extended release (Bydureon), taken weekly
- Semaglutide (Ozempic), taken weekly
- Liraglutide (Victoza), taken daily
- Lixisenatide (Adlyxin), take daily
- Exenatide (Byetta), taken twice daily

A screenshot of a PubMed search result. The header shows the PubMed logo and search options. The main content displays the title of a clinical trial: "Semaglutide versus dulaglutide once weekly in patients with type 2 diabetes (SUSTAIN 7): a randomised, open-label, phase 3b trial." Below the title, the authors and journal information are listed.

PubMed.gov  
US National Library of Medicine  
National Institutes of Health  
Advanced

Format: Abstract ▾

Lancet Diabetes Endocrinol. 2018 Apr;6(4):275-286. doi: 10.1016/S2213-8587(18)30024-X. Epub 2018 Feb 1.

**Semaglutide versus dulaglutide once weekly in patients with type 2 diabetes (SUSTAIN 7): a randomised, open-label, phase 3b trial.**

Pratley RE<sup>1</sup>, Aroda VR<sup>2</sup>, Lingvay I<sup>3</sup>, Lüdemann J<sup>4</sup>, Andreassen C<sup>5</sup>, Navarria A<sup>5</sup>, Viljoen A<sup>6</sup>, SUSTAIN 7 investigators.

⊕ Author information

<https://www.mayoclinic.org/diseases-conditions/type-2-diabetes/expert-answers/byetta/FAQ-20057955?p=1>



# ClinicalTrials.gov



Open ClinicalTrials.gov to show research activity in Augusta and Georgia

Status	Study Title	Conditions	Interventions	Locations
Recruiting NEW	<a href="#">Mental Activity During (TMS) Therapy for Depression</a>	<ul style="list-style-type: none"> <li>Cognitive Impairment</li> </ul>	<ul style="list-style-type: none"> <li>Behavioral: TMS and Lumosity@cognitive retraining</li> <li>Behavioral: TMS and non cognitive computer games</li> </ul>	<ul style="list-style-type: none"> <li>Augusta University Augusta, Georgia, United States</li> </ul>
Not yet recruiting	<a href="#">Comparison of Intrathecal Versus Epidural Fentanyl on Fetal Bradycardia in Labor Combined Spinal Epidural Analgesia</a>	<ul style="list-style-type: none"> <li>Labor Pain</li> <li>Obstetric Pain</li> </ul>	<ul style="list-style-type: none"> <li>Drug: Spinal fentanyl</li> <li>Drug: Spinal bupivacaine</li> <li>Drug: Spinal Fentanyl and Bupivacaine</li> <li>Drug: Epidural fentanyl /spinal bupivacaine</li> </ul>	<ul style="list-style-type: none"> <li>Augusta University Augusta, Georgia, United States</li> </ul>



# Clinical trials research process

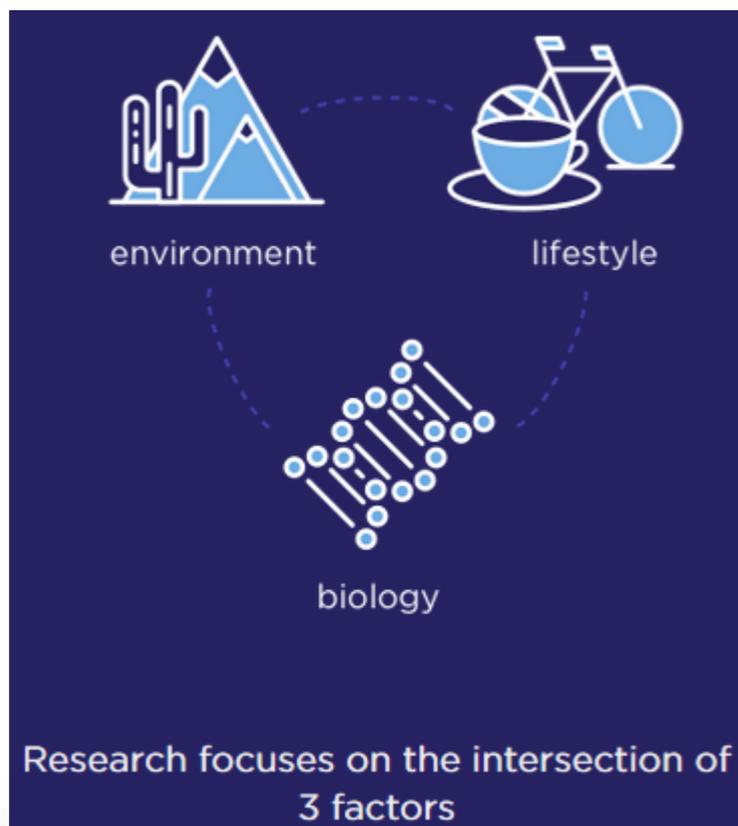
- Reason for doing the trial
- Who can join the trial (eligibility)
- How many are needed in the trial
- What treatment will be given, how it will be given, the amount, and how often
- What medical tests are done and how often
- What types of information will be collected about people taking part



# All of Us

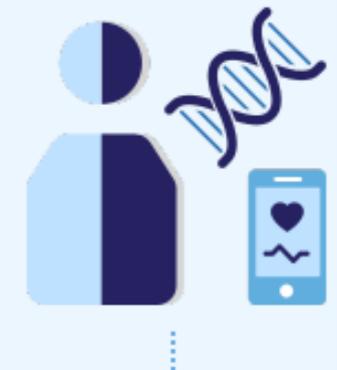


Good presentation content is available – video clips, precision medicine approaches, infographics



## Participants Share Data

Participants share health data online. This data includes health surveys and electronic health records. Participants also may be asked to share physical measurements and blood and urine samples.



## Participants Get Information

Participants will get information back about the data they provide, which may help them learn more about their health.



# Settings

- Programs at public libraries, federally-qualified health centers
- Health fair setting not appropriate
- Willing to do multiple presentations same day to reach more people



# Final thoughts

- Consumer health is a lure
- Explain benefits and risks of research
- Show how they can get involved in All of Us
- Thirty minute presentation



# Acknowledgment

*“Developed resources reported in this presentation are supported by the National Library of Medicine (NLM), National Institutes of Health (NIH) under cooperative agreement number UG4LM012340 with the University of Maryland, Health Sciences and Human Services Library. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”*



AUGUSTA UNIVERSITY

Robert B. Greenblatt, M.D.  
Library