UNIVERSITY OF MARYLAND
MPOWERING THE STATE

How Do We Assess Authenticity?

C. Daniel Mullins, PhD

Professor and Chair
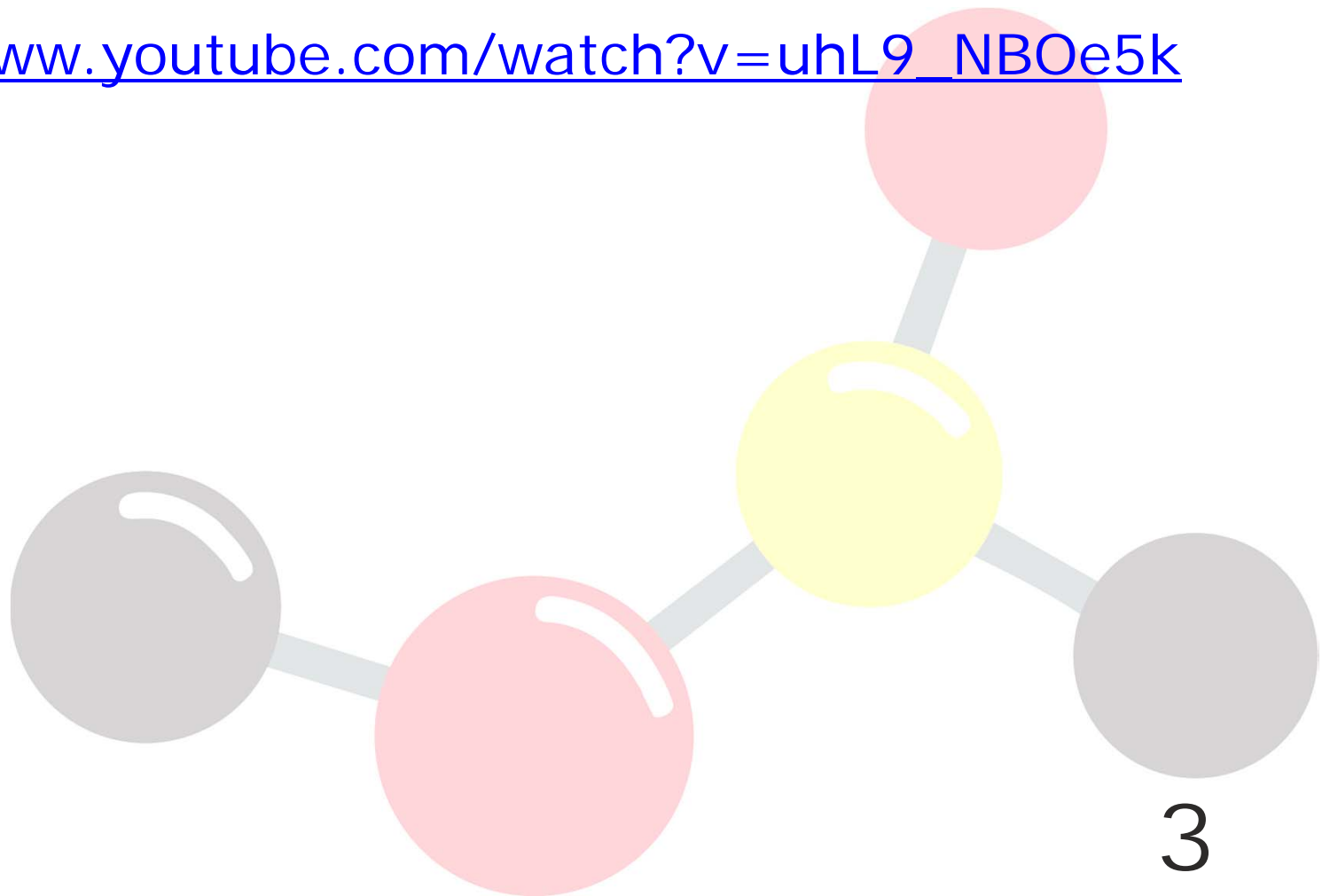Pharmaceutical Health Services Research Department
PATIENTS Program Director
Supported by AHRQ (R24HS022135)

2

Video

https://www.youtube.com/watch?v=uhL9_NBOe5k

3

Objectives

- Construct a process for building trust with communities and patients that results in authentic partnerships

- Delineate 10-Step Framework for engaging patients

- Describe how community engagement and community-based participatory research (CBPR) make health-related research more meaningful to patients

4

Building Trust: How?

Building/Maintaining Trust and Respect

Identifying → Partnering → Explaining → Doing → Updating

Building/Maintaining Trust and Respect

5
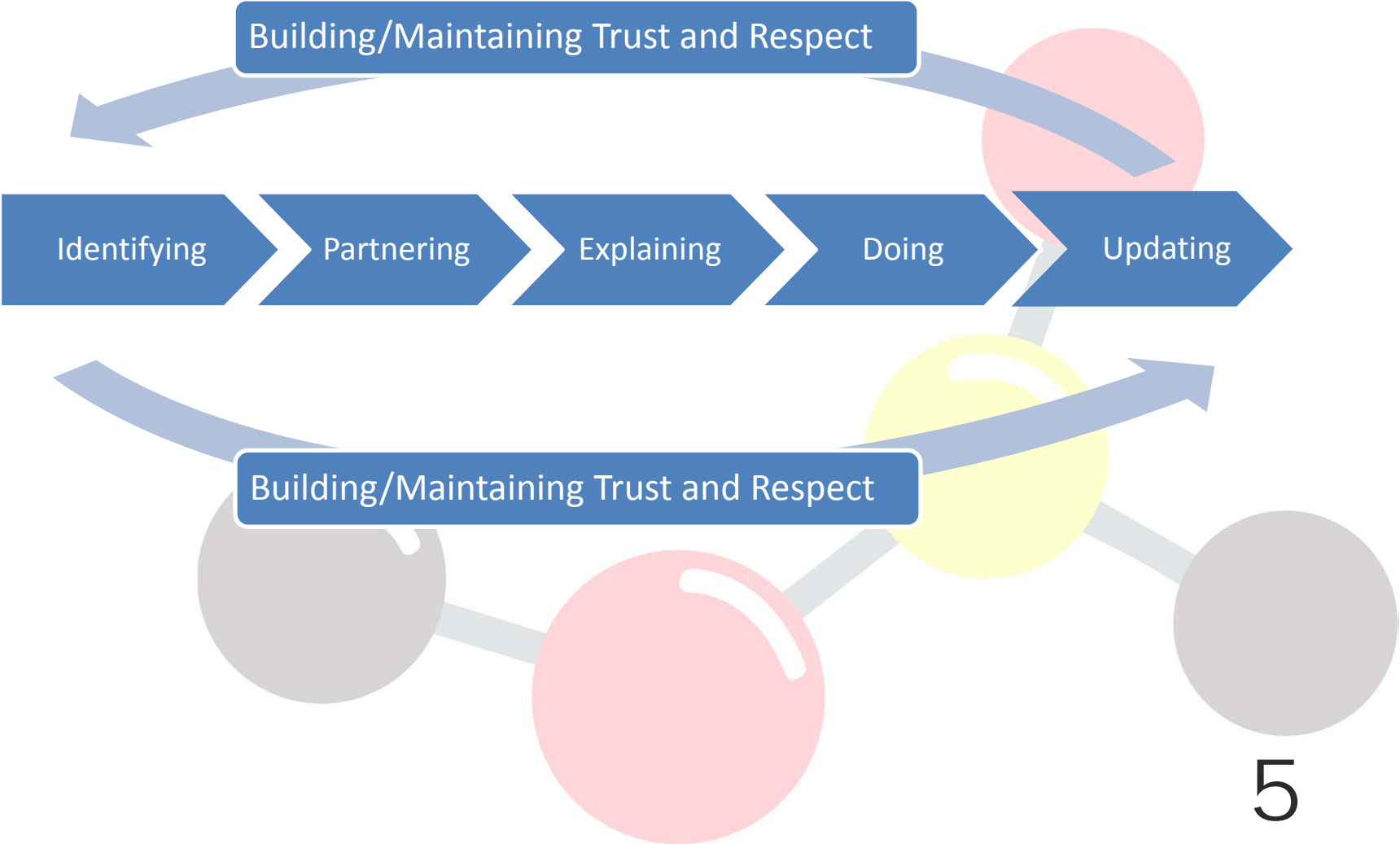
Pre-engagement

Prior to implementing a study, investigators should utilize a period of "pre-engagement" when recruiting research partners and participants

Allows time to:

- Assure comprehension
- Have questions answered and concerns addressed
- Discuss participation with family and friends

6

10-Step Process for Conducting CER *

Planning Research

1. Topic Solicitation
2. Prioritization
3. Framing the Question
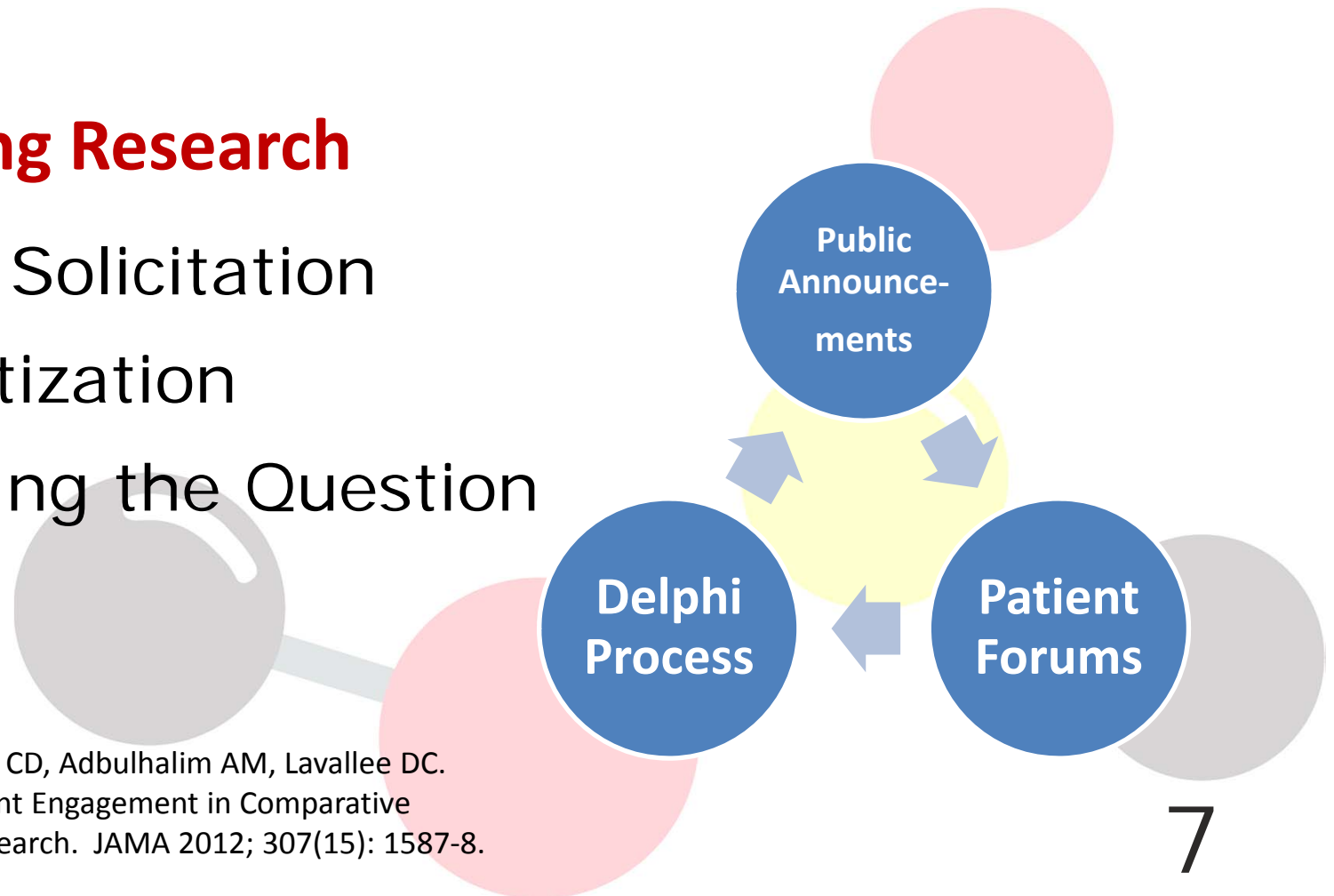
Public Announce-ments

Delphi Process

Patient Forums

* Based on Mullins CD, Adbulhalim AM, Lavallee DC.
Continuous Patient Engagement in Comparative
Effectiveness Research. JAMA 2012; 307(15): 1587-8.

7

10-Step Process for Conducting CER *

"Doing It"

4. Selection of Comparators and Outcomes
5. Creation of Conceptual Framework
6. Analysis Plan
7. Data Collection

* Based on Mullins CD, Adbulhalim AM, Lavallee DC. Continuous Patient Engagement in Comparative Effectiveness Research. JAMA 2012; 307(15): 1587-8.

In-person Meetings

Focus Group Interviews

Teleconferences

Electronic Social Media

Telephone Calls

8

10-Step Process for Conducting CER *

Delivering Solutions

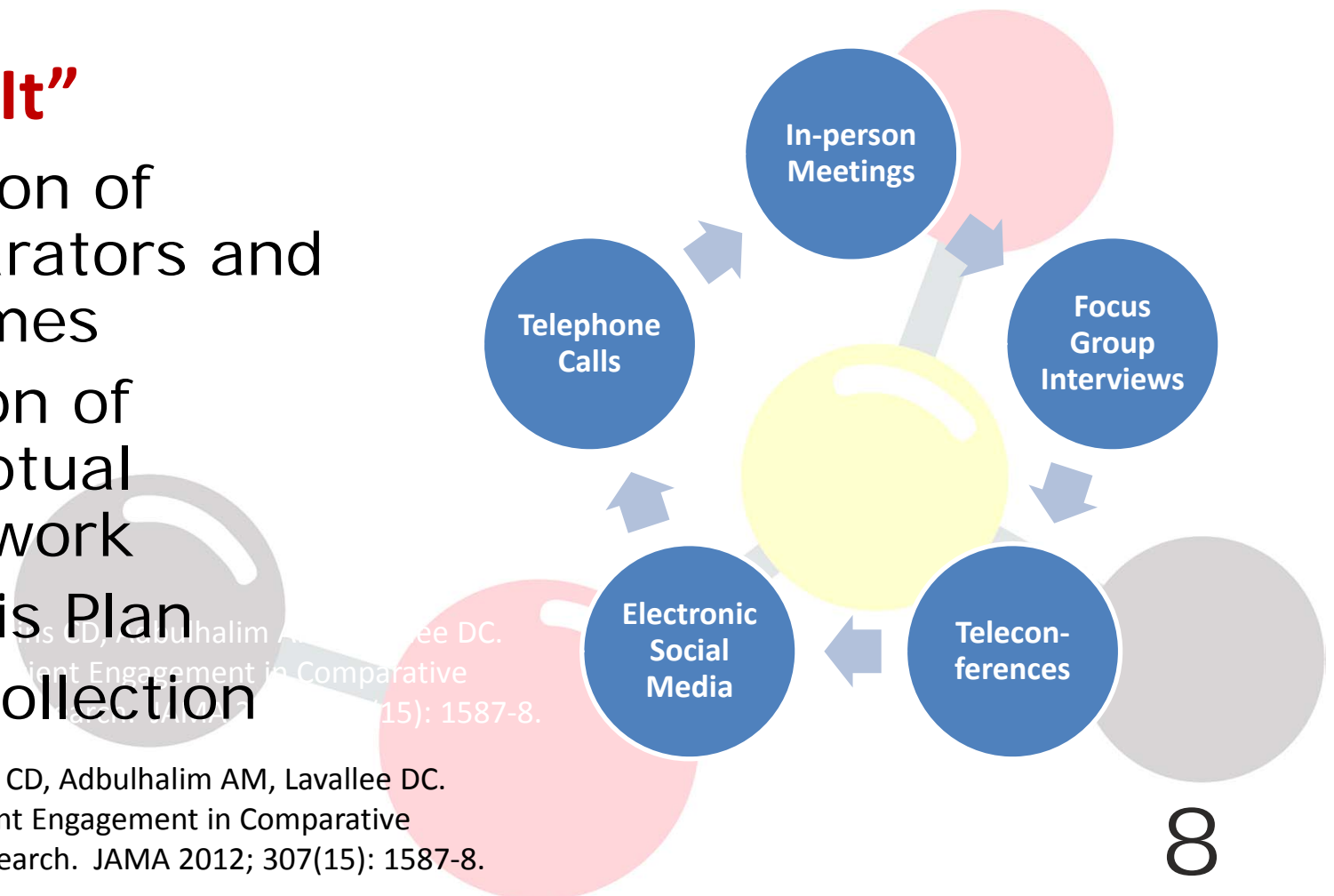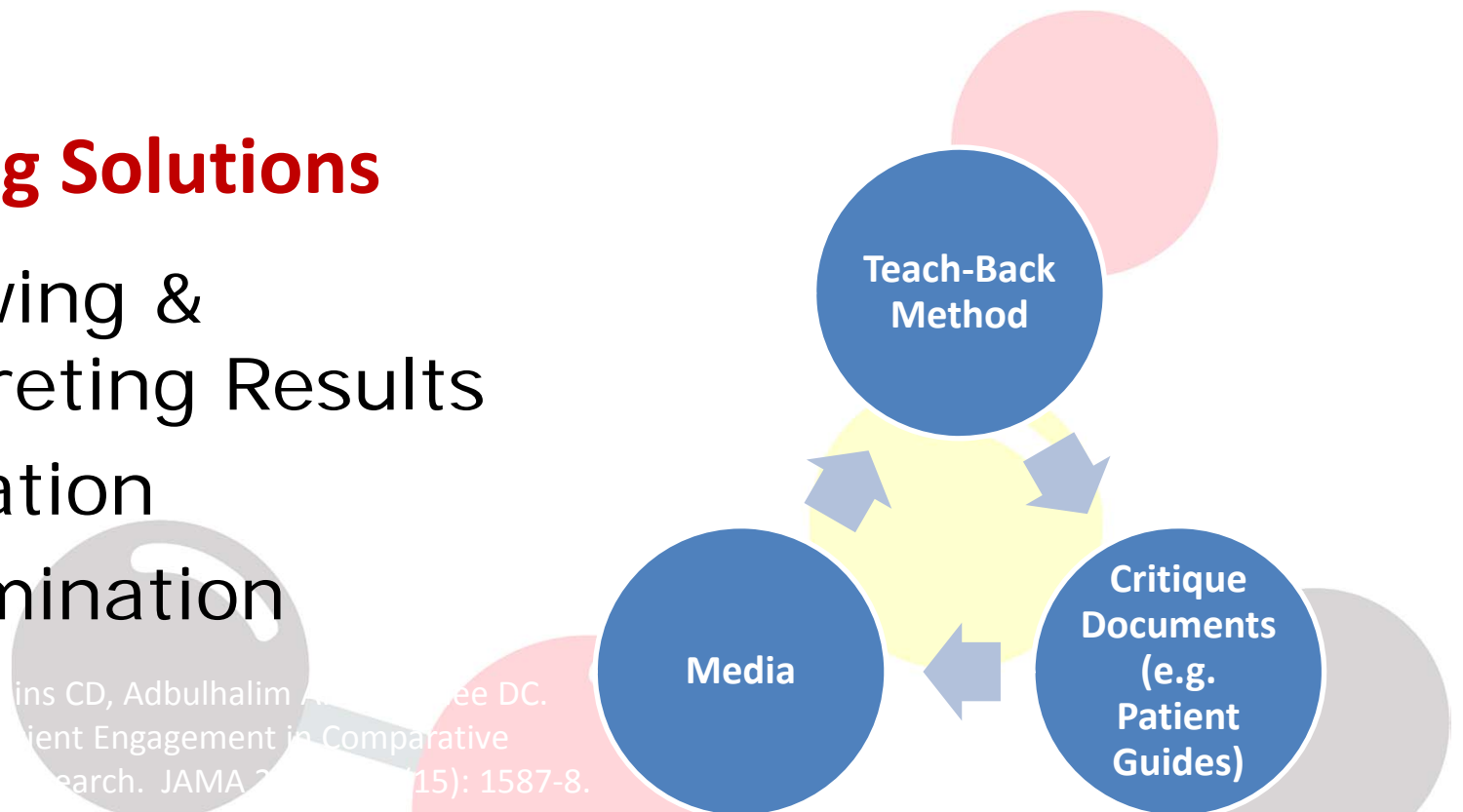8. Reviewing & Interpreting Results
9. Translation
10. Dissemination

* Based on Mullins CD, Adbulhalim AM, Lavallee DC. Continuous Patient Engagement in Comparative Effectiveness Research. JAMA 2012; 307(15): 1587-8.

Teach-Back Method

Media

Critique Documents (e.g. Patient Guides)

9

Using CBPR in patient-centered studies

Application of community-based participatory research principles to phases of a patient-centered outcomes research study	
Pre-engagement	#1 – Community as a unit of identity
	#2 – Builds on strengths, resources and relationships present within a community
	#3 – Equal partnership and collaboration in all phases of research (power sharing)

Sofolahan-Oladeinde, Y., Mullins, C. D., & Baquet, C. R. (2015). Using community-based participatory research in patient-centered outcomes research to address health disparities in under-represented communities. *Journal of comparative effectiveness research*, *4*(5), 515-523.

Using CBPR in patient-centered studies

Application of community-based participatory research principles to phases of a patient-centered outcomes research study	
Continuous engagement	#4 – Bidirectional learning and capacity building for knowledge transfer
	#5 – Integration and balance of research and action for the mutual benefit of all partners to achieve social change
	#6 – Focus on locally relevant multiple determinants of health and local capacity building

Sofolahan-Oladeinde, Y., Mullins, C. D., & Baquet, C. R. (2015). Using community-based participatory research in patient-centered outcomes research to address health disparities in under-represented communities. *Journal of comparative effectiveness research*, *4*(5), 515-523.

Using CBPR in patient-centered studies

Application of community-based participatory research principles to phases of a patient-centered outcomes research study	
Sustained engagement	#7 – Systems development through a cyclical and iterative process
	#8 – Involvement of all partners in the dissemination of findings
	#9 – Long-term commitments to ensure sustainability

Sofolahan-Oladeinde, Y., Mullins, C. D., & Baquet, C. R. (2015). Using community-based participatory research in patient-centered outcomes research to address health disparities in under-represented communities. *Journal of comparative effectiveness research*, *4*(5), 515-523.

12

Evaluating Impact

Local Community Impact			
Activity	Structure	Process	Outcomes
• Community Health Assessment • Implementation of improvement strategies • Evaluation/research	• Community Coalitions • Community channels between UMB and community • Intramural and Extramural funding	• Leadership engagement • Community participation in UMB activities • Bi-directional research translation	• Improved community health-metrics • Changes in local policies
• Community education	• Faculty and staff engagement	• Scope and topics • # of individuals engaged	• # of learners in community coalitions represented • Learning assessments

Szilagyi, P. G., Shone, L. P., Dozier, A. M., Newton, G. L., Green, T., & Bennett, N. M. (2014). Evaluating community engagement in an academic medical center. *Academic Medicine*, *89*(4), 585-595.

Evaluating Impact

National/Global Impact			
Activity	Structure	Process	Outcomes
Community based research	• Grants • CER projects	• Dissemination of findings • Translation into clinical and community settings	• # of research projects • Impact on community health
Practice based research	• Development and sustainability of practice based research	• Involved in practice-based research • Content investigated	• Impact on practice quality • Impact on health outcomes in research
National education and collaborations	• Participation in national educational efforts	• Content investigated	• Publications • Framework Dissemination
National/global advocacy	• Projects targeted to health policy and advocacy	• Evaluation & Dissemination of research conclusions	• National policies affected

Szilagyi, P. G., Shone, L. P., Dozier, A. M., Newton, G. L., Green, T., & Bennett, N. M. (2014). Evaluating community engagement in an academic medical center. *Academic Medicine*, *89*(4), 585-595.

14

Good to Great
by Jim Collins

"Think about it for one minute. Why do most overhyped change programs ultimately fail? Because they lack accountability, they fail to achieve credibility, and they have no authenticity."

Successful Partnerships

- Include:
  - Mutual trust
  - Open communication
  - Mutual respect
  - Joint participation/division of labor
  - Tangible benefits to partners
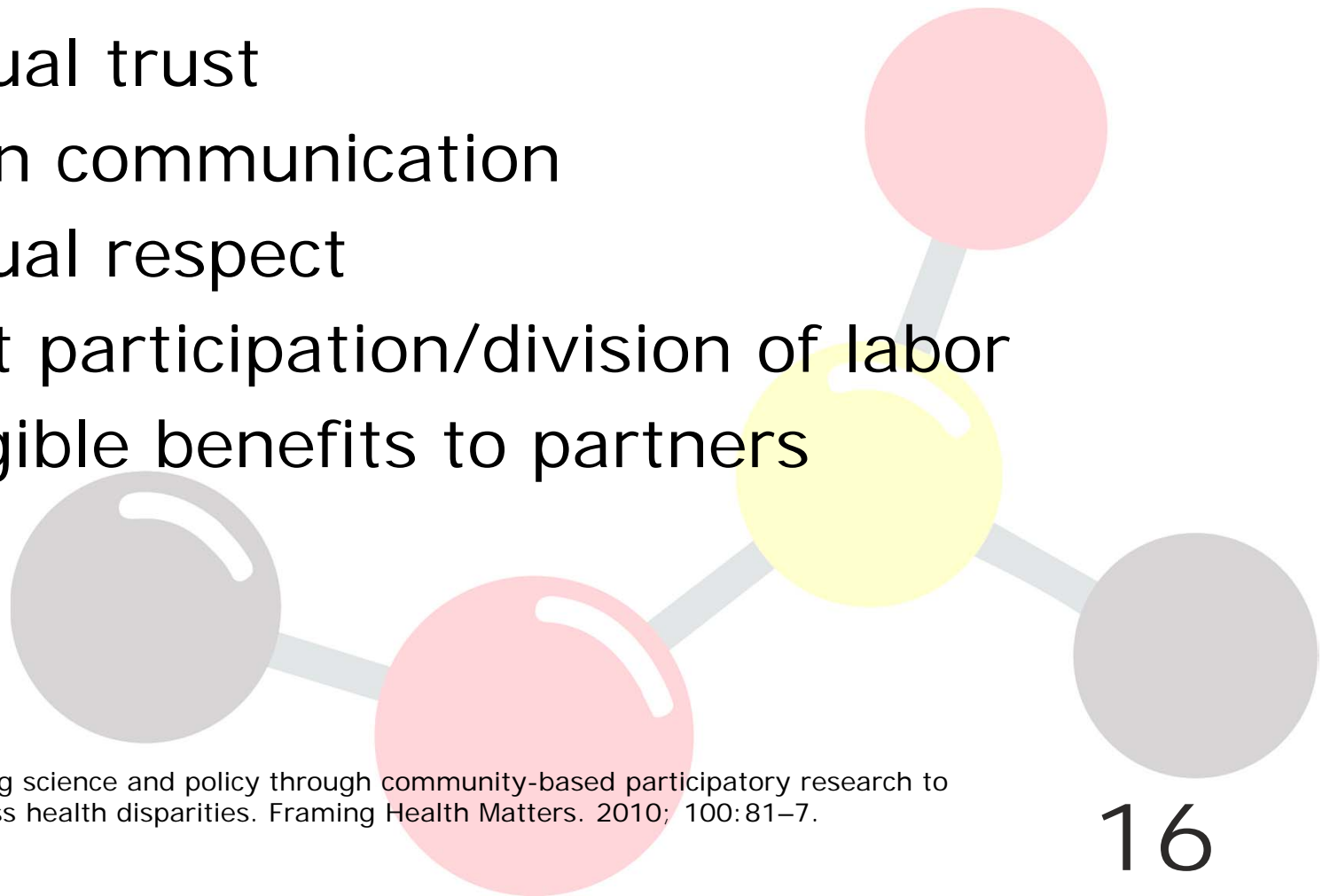
Minkler M. Linking science and policy through community-based participatory research to study and address health disparities. Framing Health Matters. 2010; 100:81–7.

16

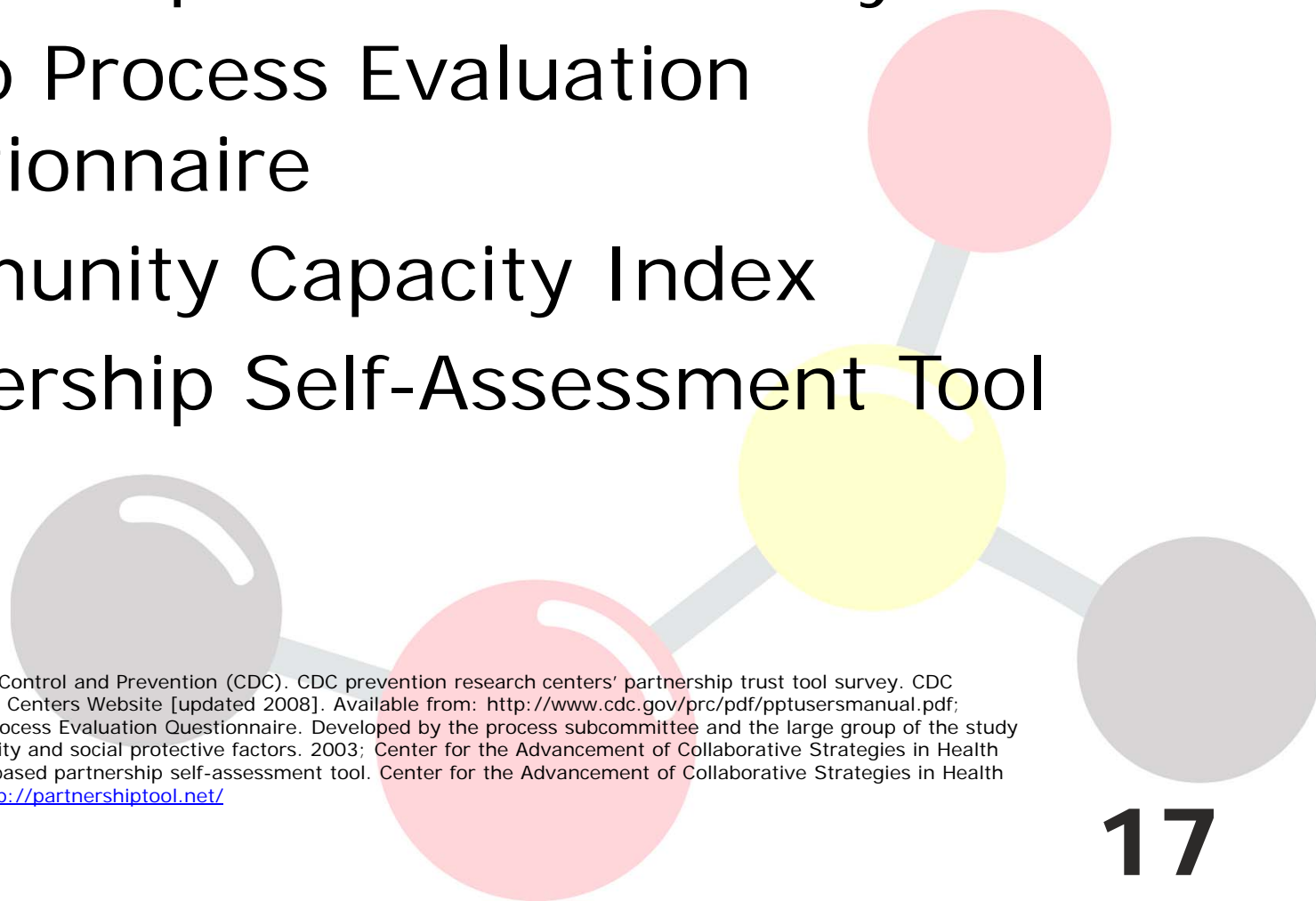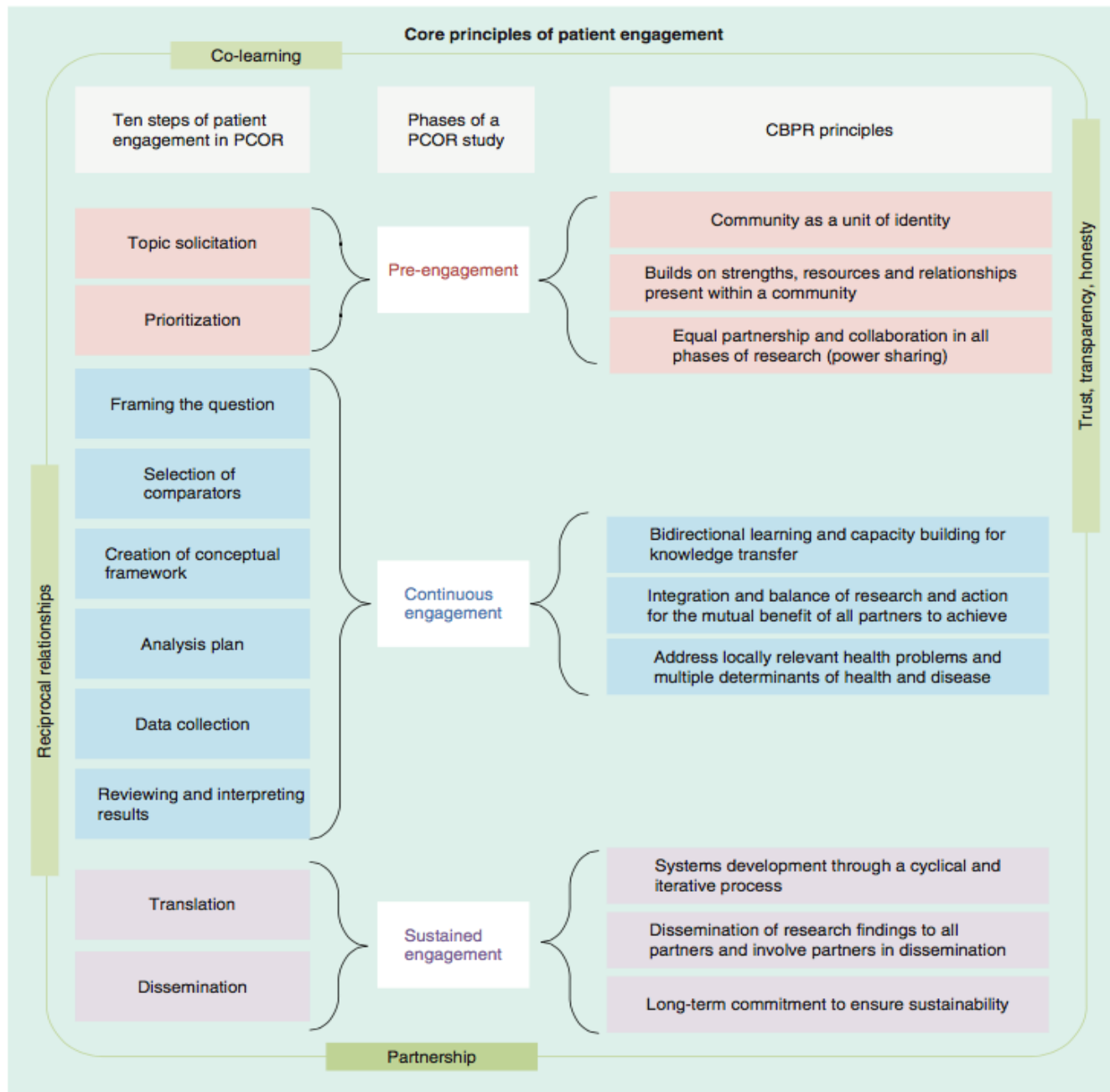# Existing Partnership Measures

- Partnership Trust Tool Survey
- Group Process Evaluation Questionnaire
- Community Capacity Index
- Partnership Self-Assessment Tool

Centers for Disease Control and Prevention (CDC). CDC prevention research centers' partnership trust tool survey. CDC Prevention Research Centers Website [updated 2008]. Available from: http://www.cdc.gov/prc/pdf/pptusersmanual.pdf; Becker EA. Group Process Evaluation Questionnaire. Developed by the process subcommittee and the large group of the study of community capacity and social protective factors. 2003; Center for the Advancement of Collaborative Strategies in Health (CACSH). The web-based partnership self-assessment tool. Center for the Advancement of Collaborative Strategies in Health [updated 2006]. http://partnershiptool.net/

Synergies between the 10-Step process and CBPR principles

Core principles of patient engagement

Ten steps of patient engagement in PCOR	Phases of a PCOR study	CBPR principles
Topic solicitation	Pre-engagement	Community as a unit of identity
Prioritization		Builds on strengths, resources and relationships present within a community
		Equal partnership and collaboration in all phases of research (power sharing)
Framing the question		
Selection of comparators		
Creation of conceptual framework	Continuous engagement	Bidirectional learning and capacity building for knowledge transfer
Analysis plan		Integration and balance of research and action for the mutual benefit of all partners to achieve
Data collection		Address locally relevant health problems and multiple determinants of health and disease
Reviewing and interpreting results		
Translation	Sustained engagement	Systems development through a cyclical and iterative process
Dissemination		Dissemination of research findings to all partners and involve partners in dissemination
		Long-term commitment to ensure sustainability

Co-learning · Reciprocal relationships · Partnership · Trust, transparency, honesty

Sofolahan-Oladeinde, Y., Mullins, C. D., & Baquet, C. R. (2015). Using community-based participatory research in patient-centered outcomes research to address health disparities in under-represented communities. *Journal of comparative effectiveness research*, *4*(5), 515-523.
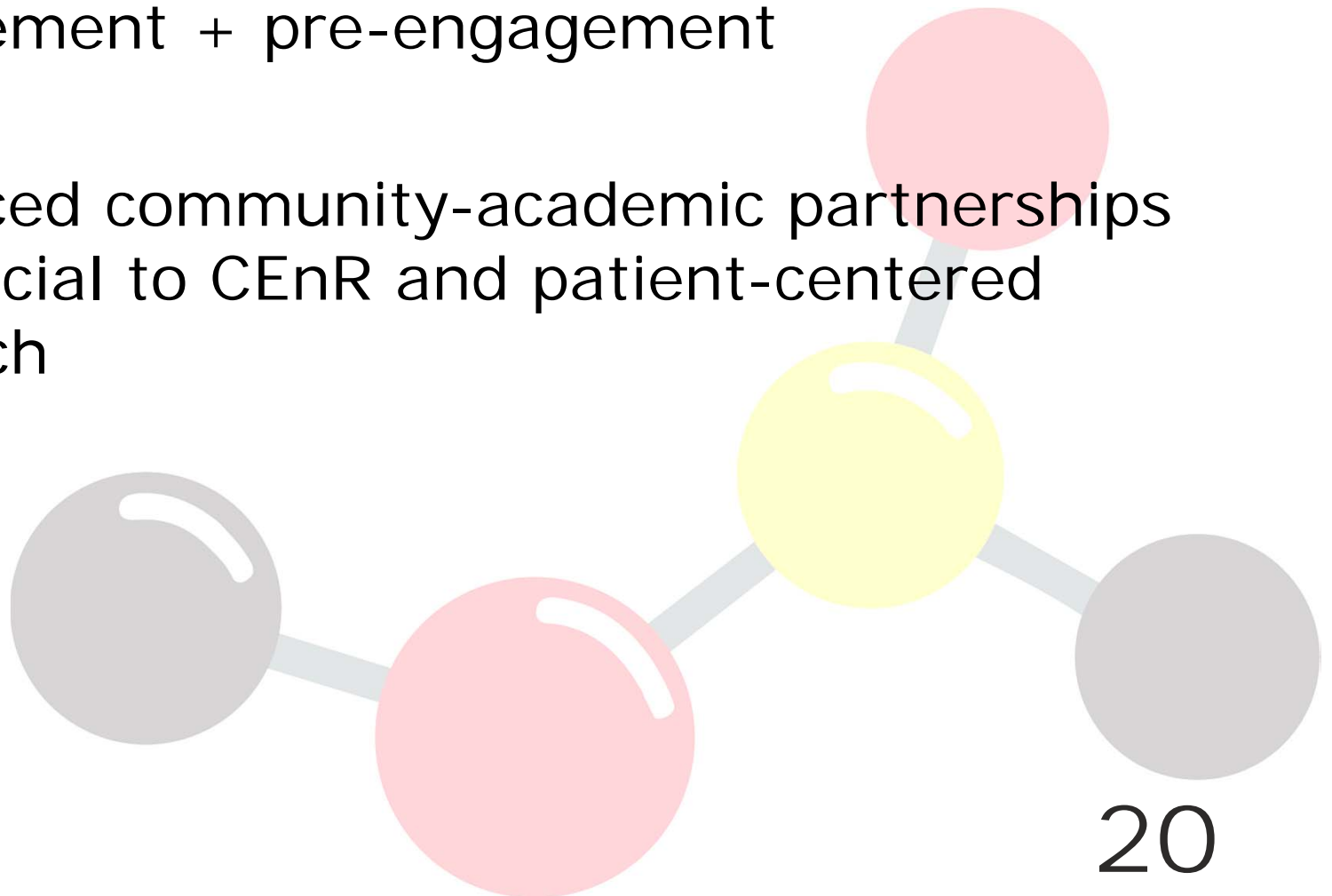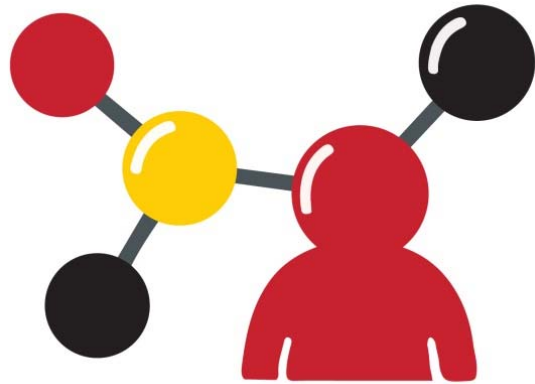
18

It's About "Being There"

- Authentic Partnerships

- Authentic Engagement

- Authentic (Honest) Data

- Authentic Desire to Improve Health

19
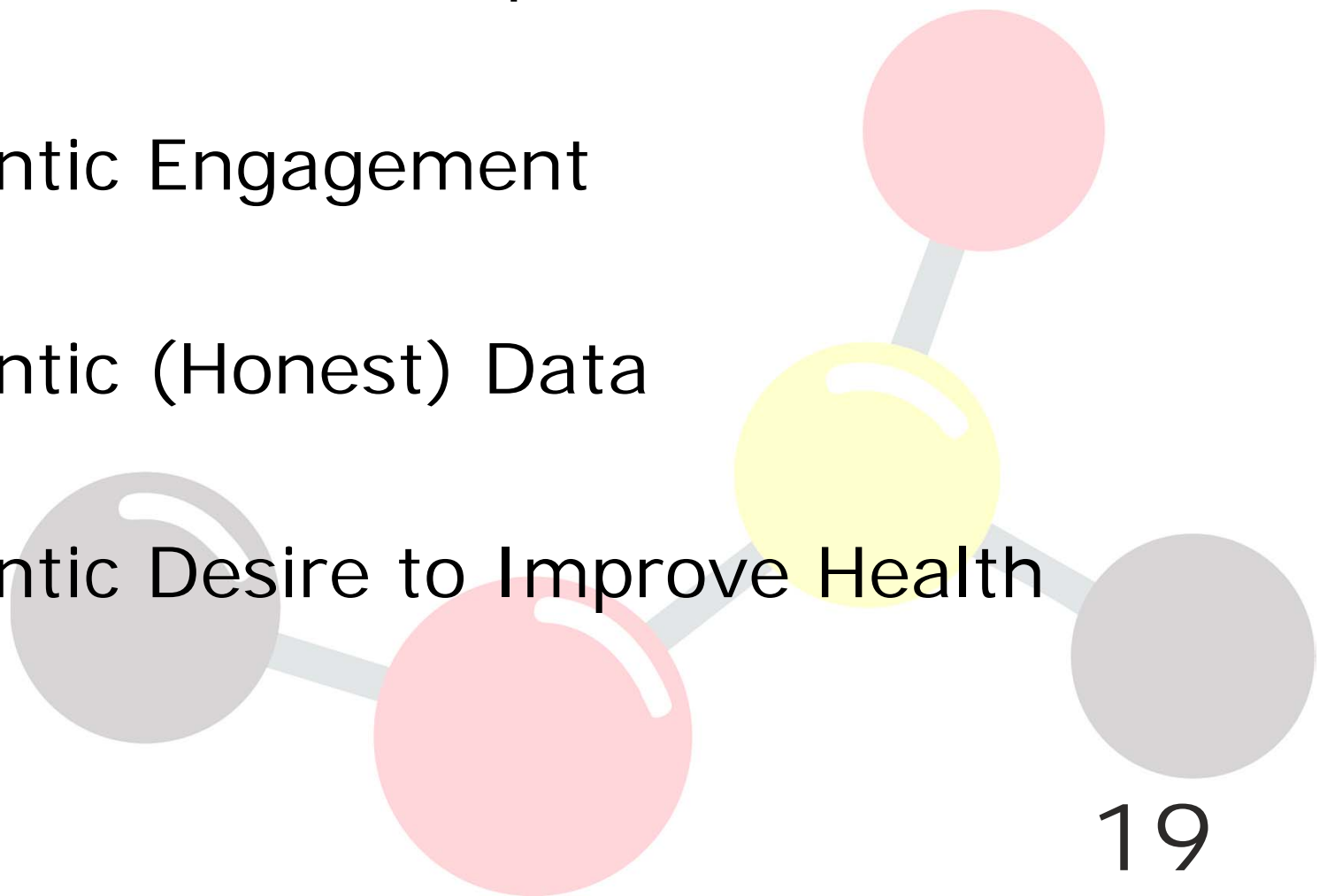
Conclusion

- Sustainable partnerships require continuous engagement + pre-engagement

- Enhanced community-academic partnerships are crucial to CEnR and patient-centered research

THANK YOU!

http://patients.umaryland.edu