Studying Patients' social networks; The design of three case studies
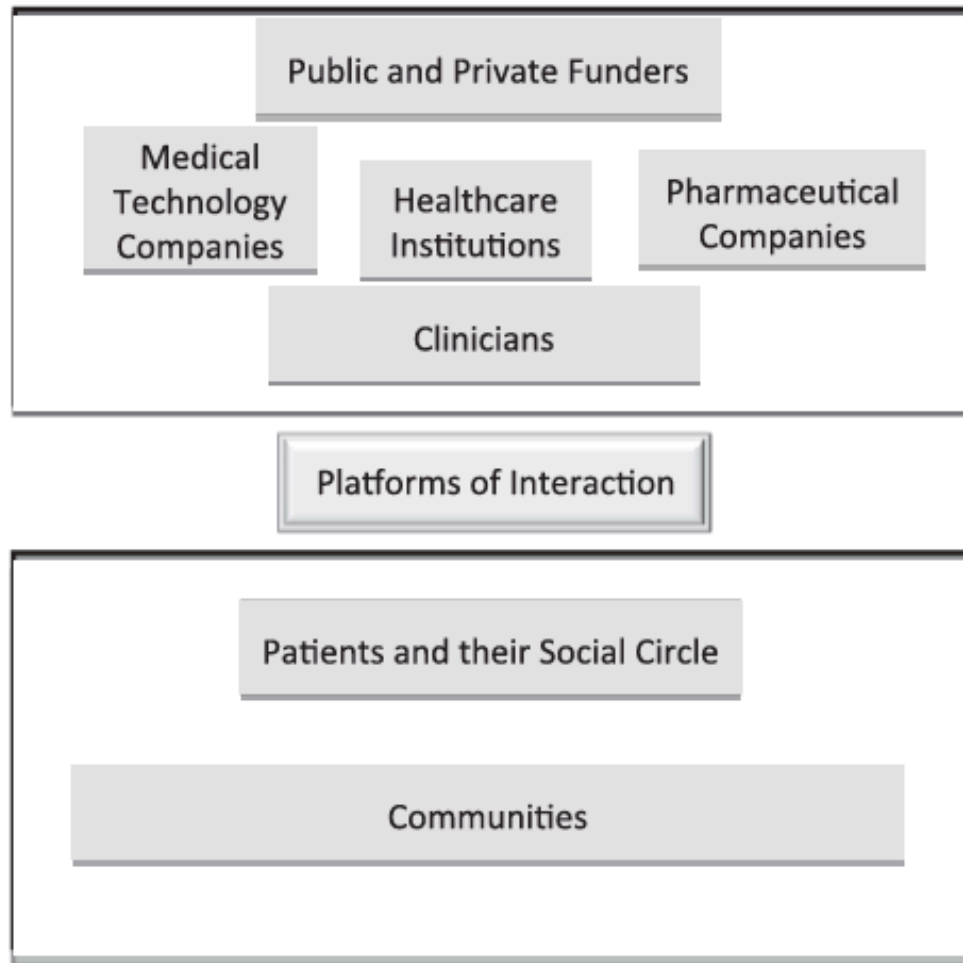
Reza Yousefi Nooraie, MD., MSc., PhD

Postdoctoral fellow
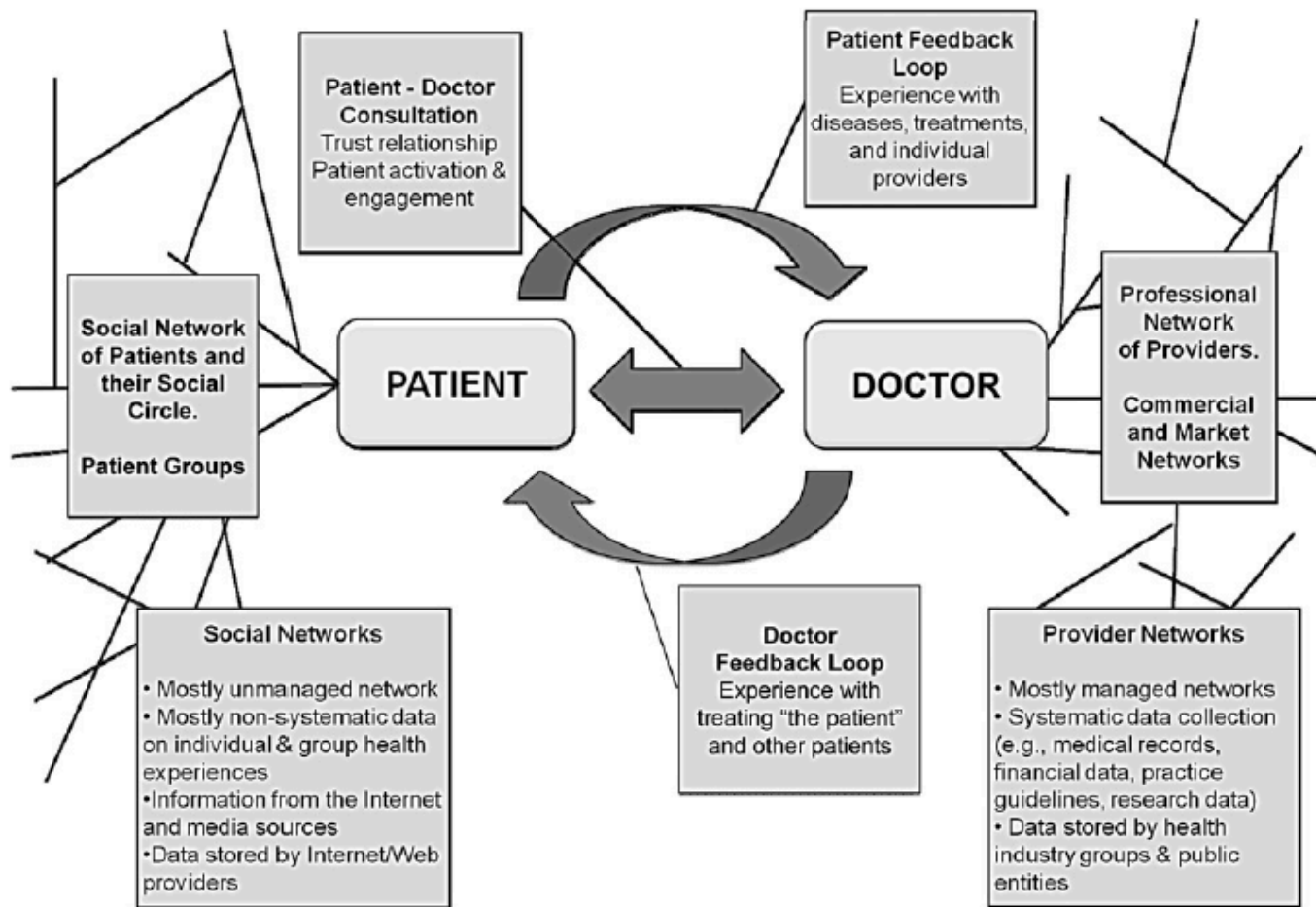
Institute of Health Policy, Management, and Evaluation (IHPME), University of Toronto
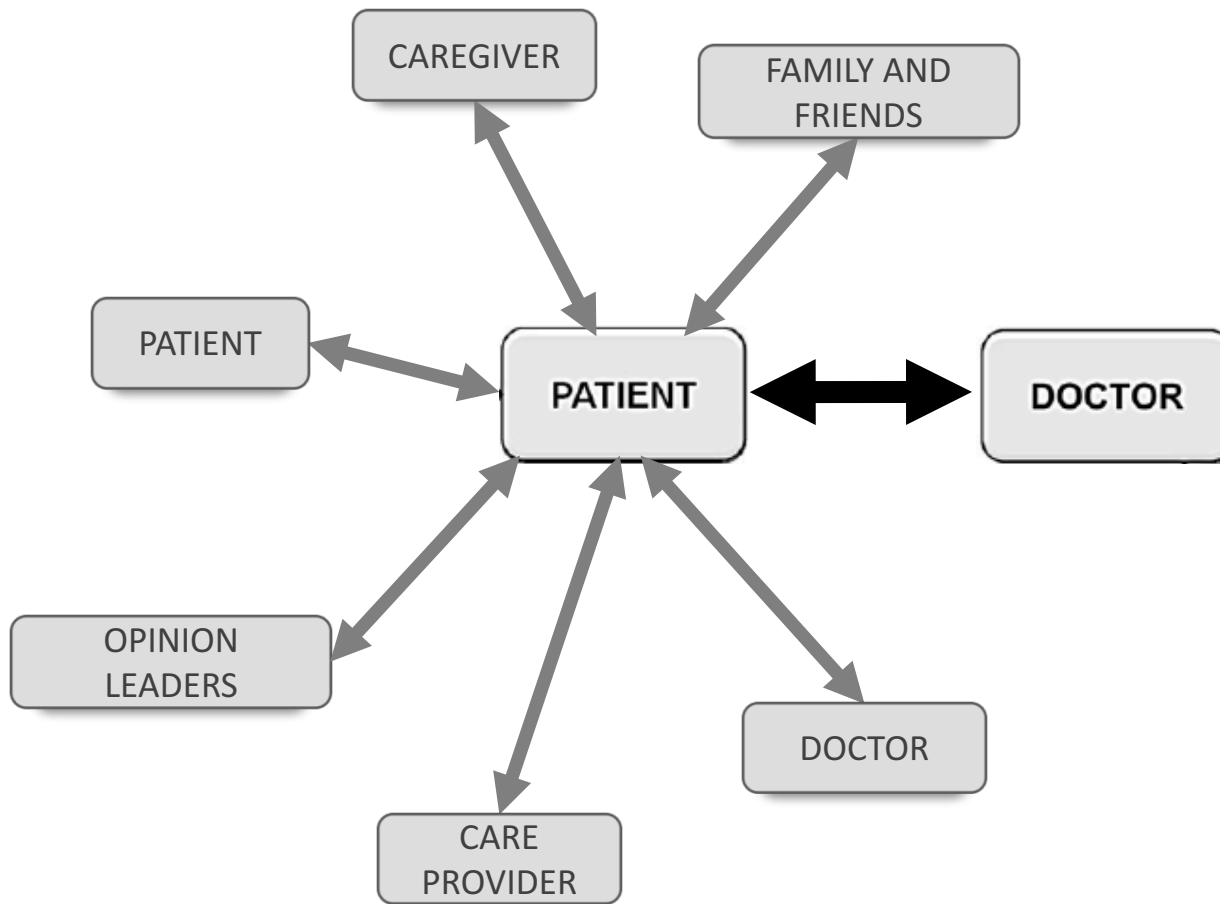
r.yousefinooraie@utoronto.ca

Health care as a two-sided network

Social networks – The future for health care delivery
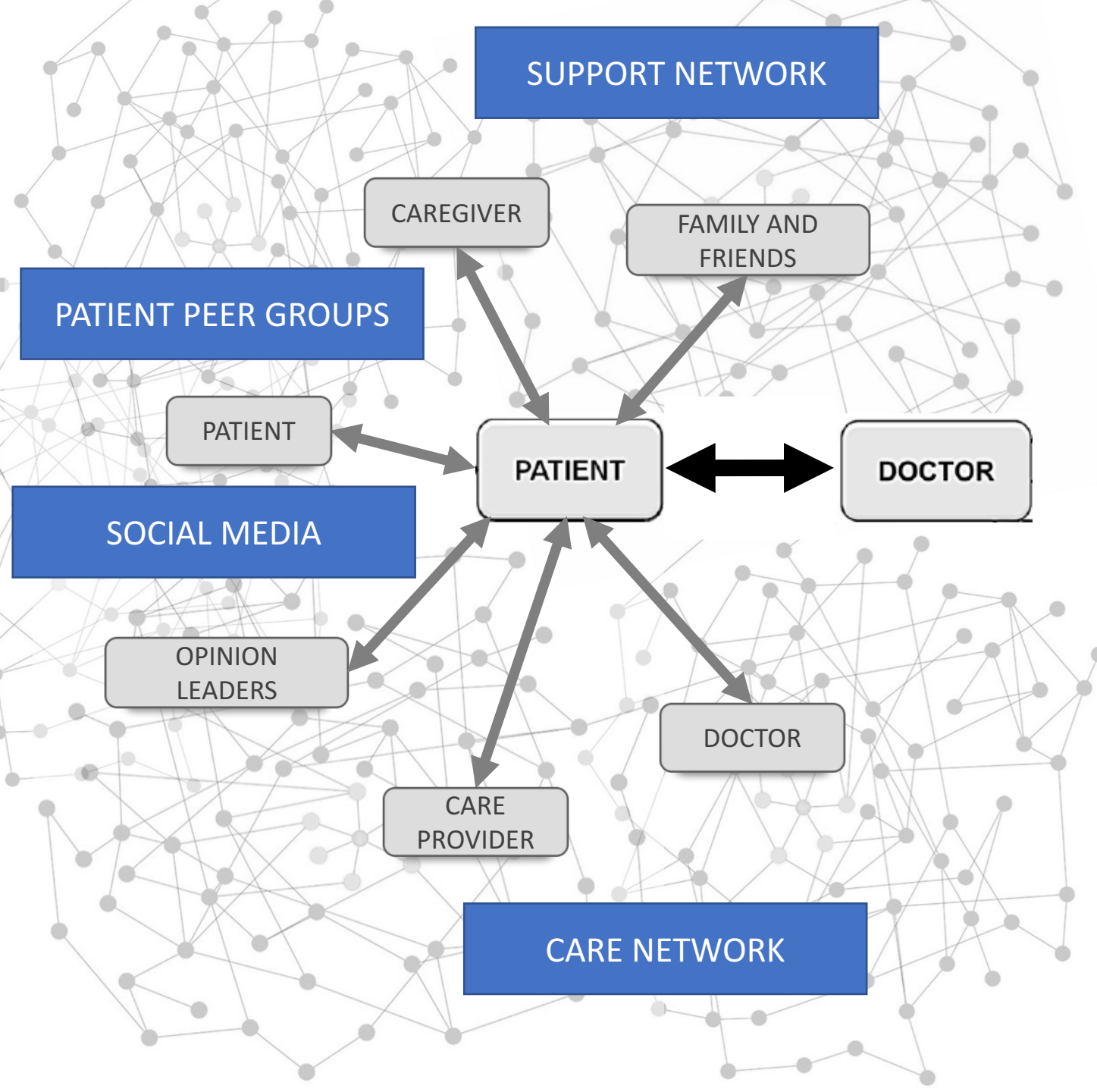(Griffiths et al. 2012)

Patient - Doctor Consultation
Trust relationship
Patient activation & engagement

Patient Feedback Loop
Experience with diseases, treatments, and individual providers

Social Network of Patients and their Social Circle.
Patient Groups

PATIENT ⟷ **DOCTOR**

Professional Network of Providers.
Commercial and Market Networks

Social Networks
• Mostly unmanaged network
• Mostly non-systematic data on individual & group health experiences
• Information from the Internet and media sources
• Data stored by Internet/Web providers

Doctor Feedback Loop
Experience with treating "the patient" and other patients

Provider Networks
• Mostly managed networks
• Systematic data collection (e.g., medical records, financial data, practice guidelines, research data)
• Data stored by health industry groups & public entities

(Griffiths et al. 2012)

Social Network Analysis

- A perspective to analyze social relationships

- A set of methods to systematically understanding and identifying social relations

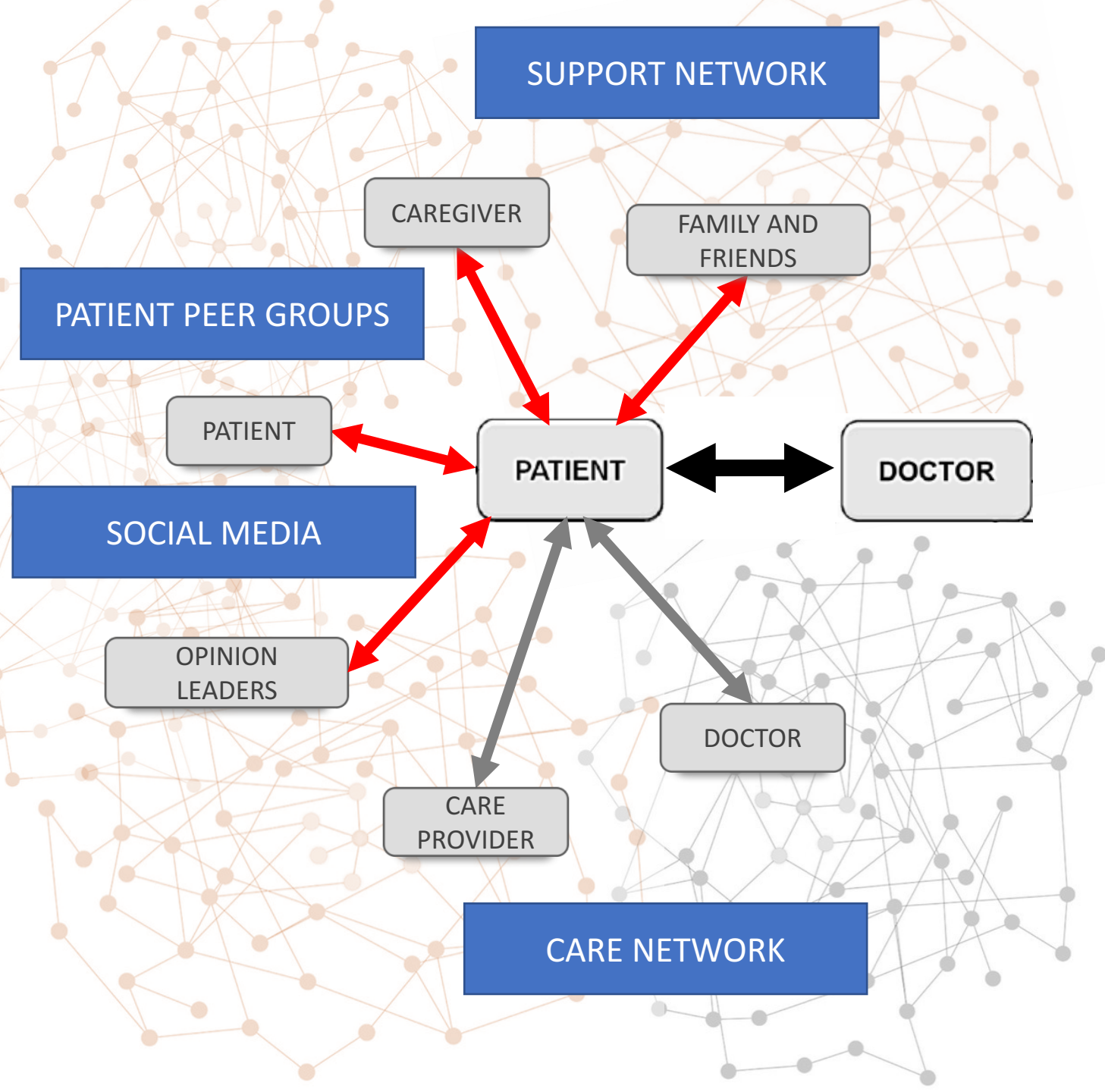- Relations and individuals as the units of analysis

- **Network as the context**
  - The composition of social networks
  - Longitudinal dynamics
  - Association between network indicators and personal attributes
- **Network as a part of the intervention**
  - Informing the interventions
  - Targeting network members
  - Altering network structures
- **Network evaluation**

Social capital

- "Resources embedded in a social structure which are accessed and/or mobilized in purposive actions" (Lin, 1999).

- Social networks provide opportunities to gain access to resources as well as benefit from each other's support

Being connected matters!

- Social support networks improve physical and mental health
- Better connected people survive longer! (Berkman and Syme 1979)

- **Social networks affect health through:**

  - the provision of social support (both perceived and actual)
  - Access to resources (e.g., money, jobs, information)

  - social influence (e.g., norms, social control)
  - person-to-person contacts (e.g., pathogen exposure, secondhand cigarette smoke)

(Berkman & Glass 2000)

Social influence

- Interactions in social networks affect the attitudes, beliefs and behaviors of individuals.

- one person's response is modified by the actions of other people
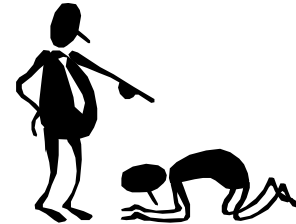
- Hierarchy vs. solidarity

The Spread of Obesity in a Large Social Network over 32 Years
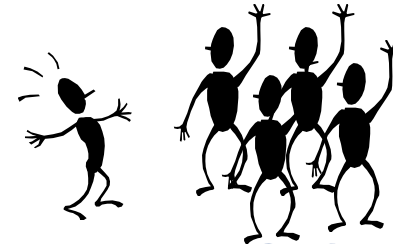## (Christakis & Fowler, 2007)

- Social network of 12,067 people assessed repeatedly from 1971 to 2003 as part of the **Framingham Heart Study**.

- longitudinal GEE model

- whether weight gain in one person was associated with weight gain in his or her friends, siblings, spouse, and neighbors.

Theoretical framework
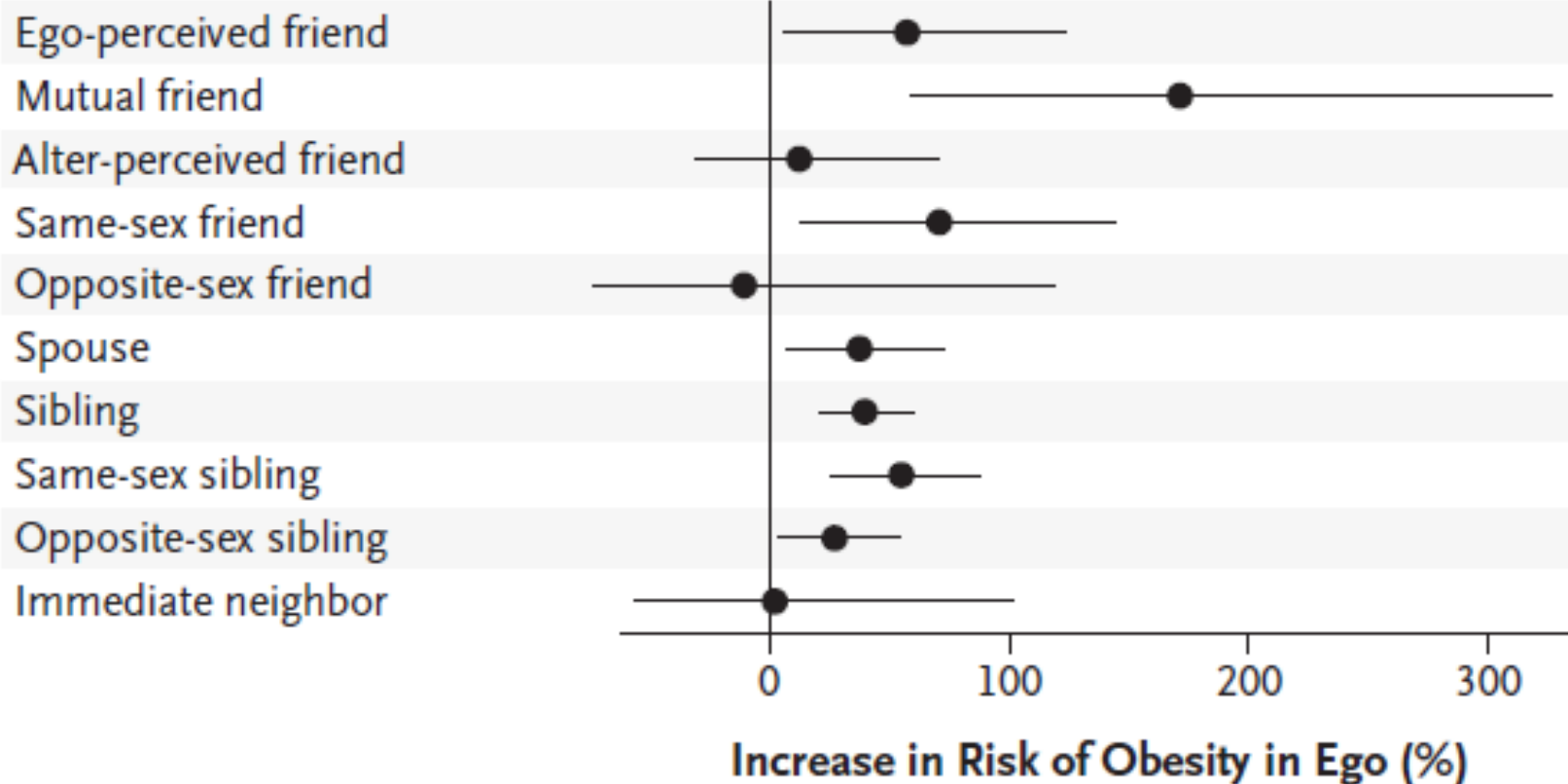
- **Social influence/induction**

- **Social selection/homophily**

- **Common context**

Alter Type

Ego-perceived friend
Mutual friend
Alter-perceived friend
Same-sex friend
Opposite-sex friend
Spouse
Sibling
Same-sex sibling
Opposite-sex sibling
Immediate neighbor

0   100   200   300

Increase in Risk of Obesity in Ego (%)

Social influence

- For each additional family members and friends with diabetes, patients expressed a greater level of concern about diabetes [OR:1.5] (Mani et al. 2011)

- A spouse with recent screening was associated with more colorectal cancer screening [OR:1.65] (Keating et al. 2011)

- Health service costs were significantly reduced for chronic disease patients receiving greater levels of illness work through their social networks (Reeves et al. 2014)

Online social networks

- Convenient connection with others in similar circumstances

- Ability to communicate anonymously

- Reciprocity of social support

Empowerment through online peer communities

- **renegotiate and normalize illness-associated identity**

- **social support and connectivity**

- **experiential knowledge sharing**

- **collective voice and mobilization**

(Kingod et al. 2017)

Empowered patient communities

- **Feedback loop to the clinical trials process**
  - PatientsLikeMe patients noticed and suggested corrections and improvements to the graphical display of data in ALS clinical trials
- **Patient-inspired/patient-run research**
  - In 2007, a patient newly diagnosed with ALS used Google to translate an Italian conference abstract suggesting that lithium might slow disease progress.
  - 250 PatinetsLikeMe patients gathered to self-experiment with lithium
  - Obtained lithium off-label and tracked their progression using Google Spreadsheets and the validated ALS functional rating scale
  - The study found that lithium did not slow disease progression.
- **Protocol violation activism**
  - Members of PatientsLikeMe report tracking their outcomes in over 400 randomized trials.

(Swan 2009, Wicks et al. 2014)

Negative influence

- Relational conflict and unwanted or insensitive advice can increase stress levels (Goldsmith and Albrecht, 2011).

- Social network members may avoid communicating with a person when it is needed most. Stigmatized health conditions (Wright and Miller, 2010; Wright and Rains, 2013).

- Credibility: Out of 345 status updates on Twitter, misinformation about flu requiring antibiotics reached a total of 172,571 followers (Scanfield 2010)
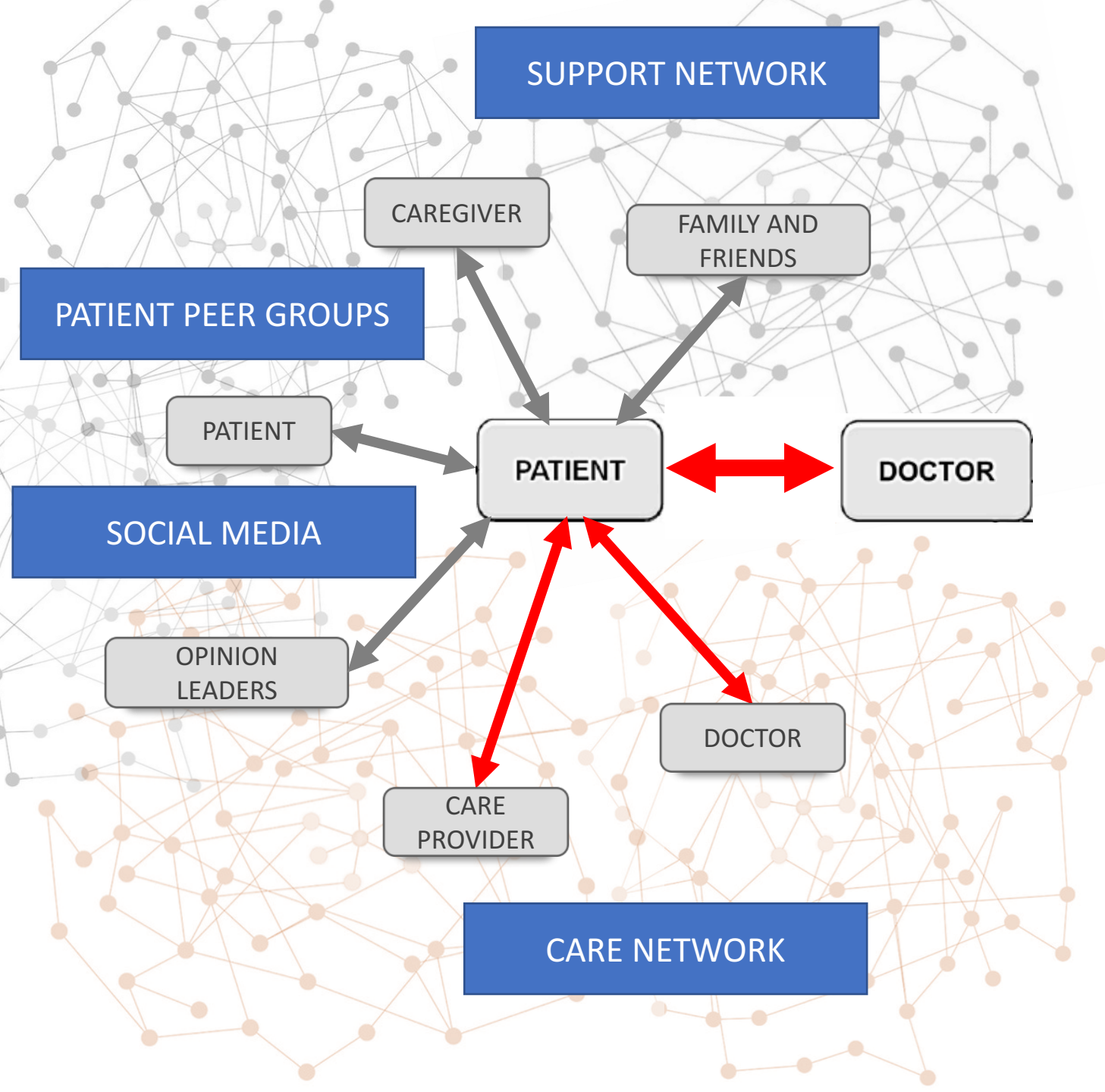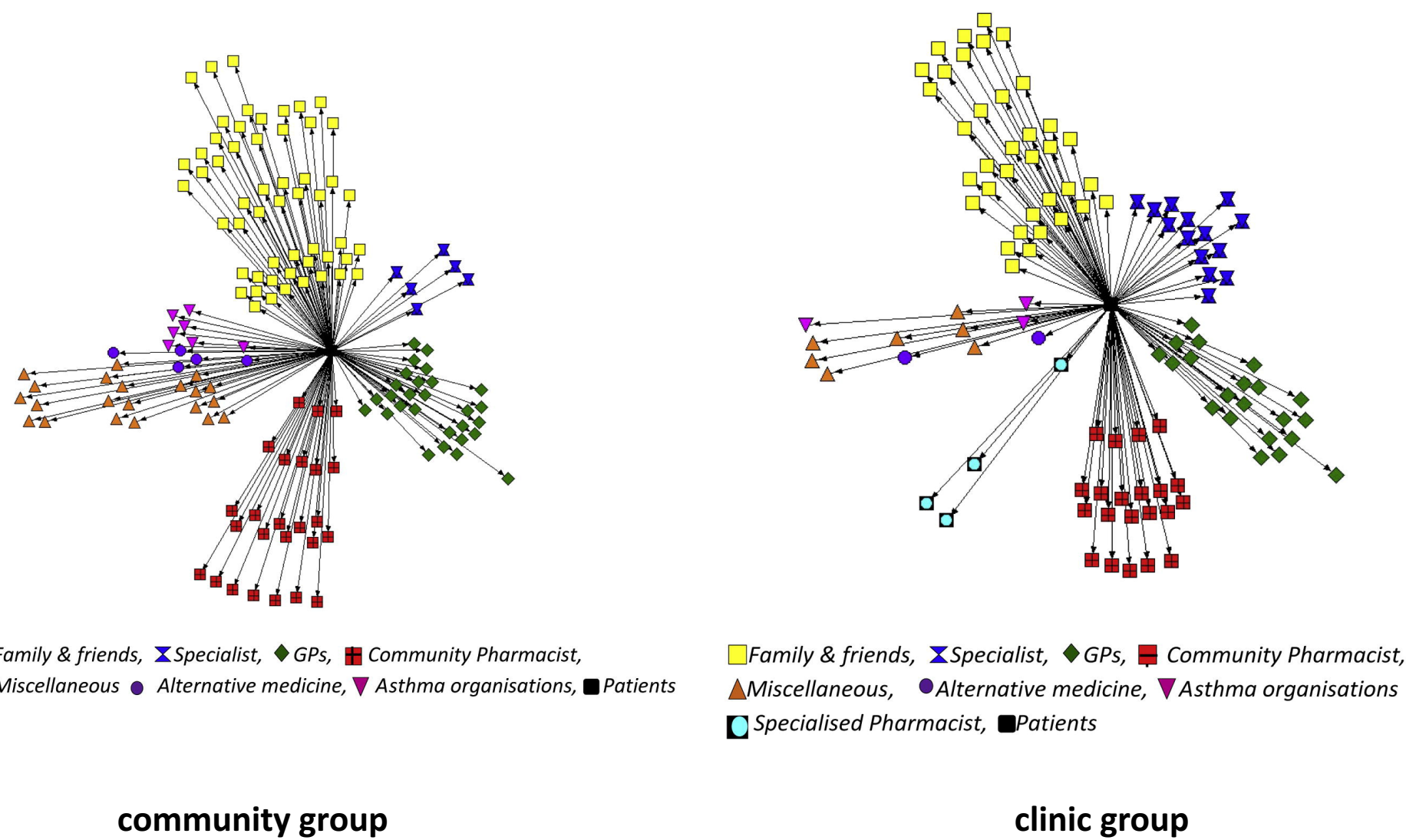
Primary health care teams and the patient perspective: A social network analysis
(Cheong et al. 2013)

- Multidisciplinary research has predominantly focused on health care providers
- Patients' selections of individuals to assist with their asthma did not necessary reflect traditional members of an MDC team.

- 47 In-depth, semi-structured interviews with asthma patients from Sydney, Australia.

- community group interacted was the GP, while the clinic group with the specialist.
- Weak ties to pharmacists in both groups
- strongly rely on lay individuals such as family and friends

Family & friends, Specialist, GPs, Community Pharmacist, Miscellaneous, Alternative medicine, Asthma organisations, Patients

community group

Family & friends, Specialist, GPs, Community Pharmacist, Miscellaneous, Alternative medicine, Asthma organisations, Specialised Pharmacist, Patients

clinic group

Network as the context

- The composition of social networks
  - *Personal network of care*

- Longitudinal dynamics
  - *Spread of obesity*

- Association between network indicators and personal attributes
  - *Network membership and health*

Network interventions

- Purposeful efforts to use social networks or social network data to generate social influence, accelerate behavior change, improve performance, and/or achieve desirable outcomes among individuals, communities, organizations, or populations.

(Valente 2012)

Network interventions

- **Network-informed intervention:**
  - identifying individuals based on some network property:
    - *Opinion leaders*
    - *Bridges*
  - Insight by network structure:
    - *intervention is directed toward a group*
- **Induction:**
  - *Word of mouth*
- **Network alteration:**
  - *Tie formation/ activation*
  - *Rewiring*

Bringing Patients' Social Context into the Examination Room: An Investigation of the Discussion of Social Influence During Contraceptive Counseling (Levy et al. 2015)

- Mixed-methods analysis of 342 contraceptive counseling visits.

- Social influences were mentioned in 42% of the 342 visits
- Discussions most commonly initiated by patients.

- Recommend that providers initiate the discussion of social influence with their patients

Health decision making as a shared process

- Social network, family members and friends, are involved in four related areas:
  - encouraging the patient to discuss the decision;
  - collaborating in the decision with the patient;
  - persuading the patient to make a decision;
  - making the decision for the patient.

- decision making is never a solo cognitive activity but rather distributed over a range of people   Rapley 2008

- Health literacy measurements and programs to develop health literacy should not only target individuals but could also be aimed at their family, friends and primary caregivers.

(Edwards et al. 2015)

Identification of opinion leaders

- someone who is able to *informally affect others' attitudes and behaviours* in a desired way

- **Sociometric** (network)
- Self identification
- Expert identification
- Known celebrities

Valente 2007

Small overlap
(Grimshaw 2006)

Identification of opinion leaders

- The Power & Perspective of Mommy Bloggers: Formative Research with Social Media Opinion Leaders about HPV Vaccination (Burke-Garci et al. 2017)

- Who is Spreading Rumours about Vaccines?: Influential User Impact Modelling in Social Networks. (Kostkova et al. 2017)

Induction

- Stimulate peer-to-peer interaction to create cascades in information/behavioral diffusion.
  - Diffusion of innovation
  - Outreach
  - marketing

- <u>Do not necessarily use network data</u>, but depend on the network structure

- Network position of initial adopters, clustering structure

Social network targeting to maximise population behaviour change: a cluster randomised controlled trial
(Kim et al. 2015)

- A cluster randomised trial of 32 villages in Honduras.
- chlorine for water and multivitamins for micronutrient deficiencies.
- randomised villages to one of three targeting methods:
  - **randomly selected villagers**
  - **villagers with the most social ties**
  - **or nominated friends of random villagers**

friendship paradox

- Targeting nominated friends increased adoption of the nutritional intervention by 12·2% compared with random targeting
- Targeting the most highly connected individuals produced no greater adoption of either intervention

31

Network alteration

- adding/deleting nodes and links

- rewiring existing links

Cohesion formation

Increases in Network Ties Are Associated With Increased Cohesion Among Intervention Participants (Gesell 2016)

- A community-based randomized controlled trial.
- A total of 305 parents with a child (3-6 years) at risk of developing obesity
- Intervention: Parents met weekly for 12 weeks in small consistent groups discussing healthy lifestyle

- Sense of cohesion increased
- Network nominations increased

Community of Practice

Network evaluation

- Change in network structure

- Change in the position of influential actors

- Sustainability of change

The example of 'Virtual Wards'

- *patients with a high risk of admission monitored by a multi-disciplinary team of care providers (via telephone, home visits, or clinic visits) after discharge.*

- The intervention failed to show a significant improvement in patient outcomes (Dhalla et al. 2014)

- **Researchers' speculation:** the role of collaboration and communication among various actors.

- A modified virtual ward model in Singapore showed highly significant effects (Low et al. 2017)

- **Researchers' speculation:** "positive culture of collaboration and teamwork"

Perspectives

- **egocentric** or personal networks
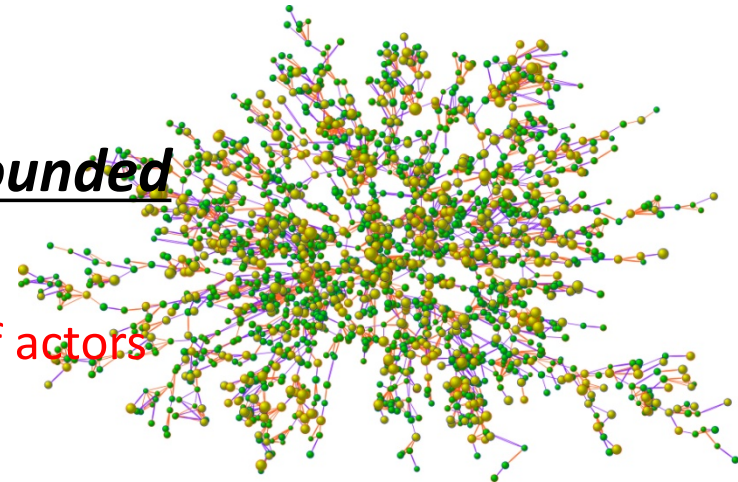 - relations defined from ***focal individuals***
    - compare relational structures of actors
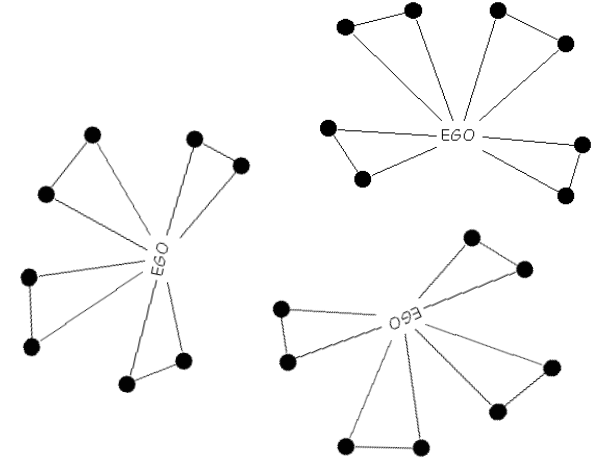
- **sociocentric** or whole networks
  - relations linking members of ***a single, bounded population***
    - examine internal structures and positioning of actors within one network

Mixed methods network analysis studies

- More indepth insight to social networks, both <u>outsider</u> and <u>insider</u> views
- **Quantitative:**
  - Bird's eye view
  - Numerical indicators and Statistical modeling
- **Qualitative:**
  - Confirming/disconfirming
  - Narrative stories, examples and Contextual mechanisms

- Qualitative data collection (sequential exploratory)

- Qualitative interpretation of network results (sequential explanatory)

Study 1: The experience of patients who are engaged in research with social networks;
a longitudinal mixed methods study of Patient Advisors Network

Investigators (in alphabetical order):

Whitney Berta, Raisa Deber, Alies Maybee, Annette McKinnon, Don Willison, Reza Yousefi Nooraie

- A case study to investigate the effects of social networking interventions to improve the process of engagement of patients in planning and conducting health research

Patient Advisors Network

Independent
Informed
Connected

- **Patient Advisors Network (PAN)** an initiative designed to build a community of patients and service users who are committed to provide advice to research and health decision making and planning.

Rationale

- Active collaboration of patients "in governance, priority setting, conducting research and knowledge translation" is widely advocated (CIHR)

- A complex process

- Patients are not always satisfied with the adequacy of communication in research teams (Crawford et al. 2002)

- Power imbalance and conflict induced by professional and hierarchical presumptions (Brett et al. 2014)

- Limited knowledge of patients' experience in social networks throughout engagement in research

- How social relations might be harnessed to enhance the experiences of patients and the productivity of engagement

It IS about us!
Patient Engagement in Health Research
Arthritis Research Canada

- qualitative interview of members of the Arthritis Patient Advisory Board

- building social relations among patient advisors was important for empowering new members.

- This was facilitated by sharing experiences about responsibilities and expectations, and forming a sense of solidarity within the group.

(Tran et al. 2016)

Quantitative strand

- A sociocentric longitudinal study of the PAN network

- conversations at four time points
- patterns of formation and evolution of social network over time.

- Two online surveys, with one year interval.
  - their recent information sharing and support relations with peers/caregivers/members of care team/others, the quality of the relations, and the themes of communication.
  - their activity and access in social media.
  - the openness, clarity, adequacy, and effectiveness of the process of their recent engagement in research
  - the impact of participation in PAN on engagement experience

How connected does the network look like?

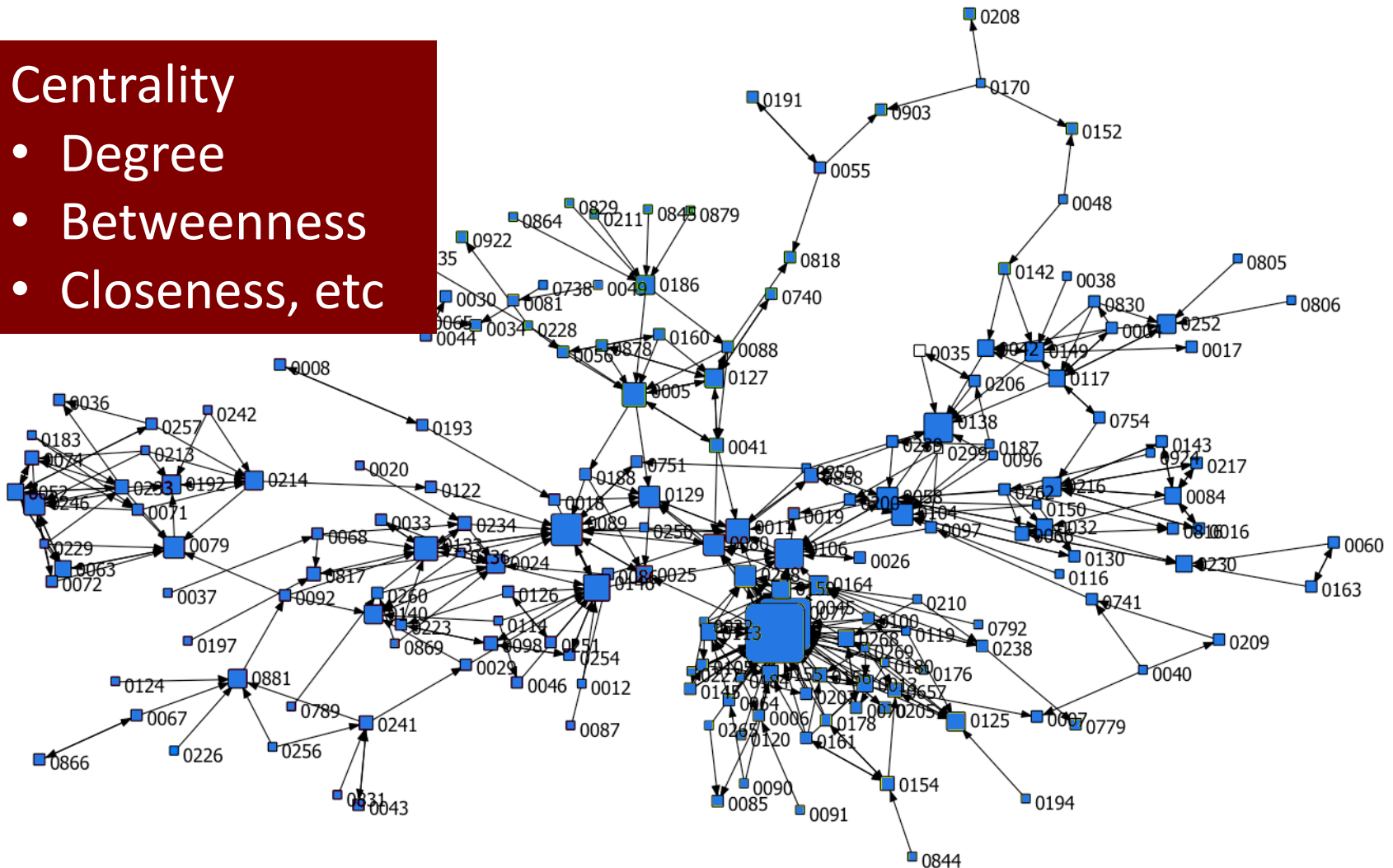- Density
- Reciprocity
- Distance
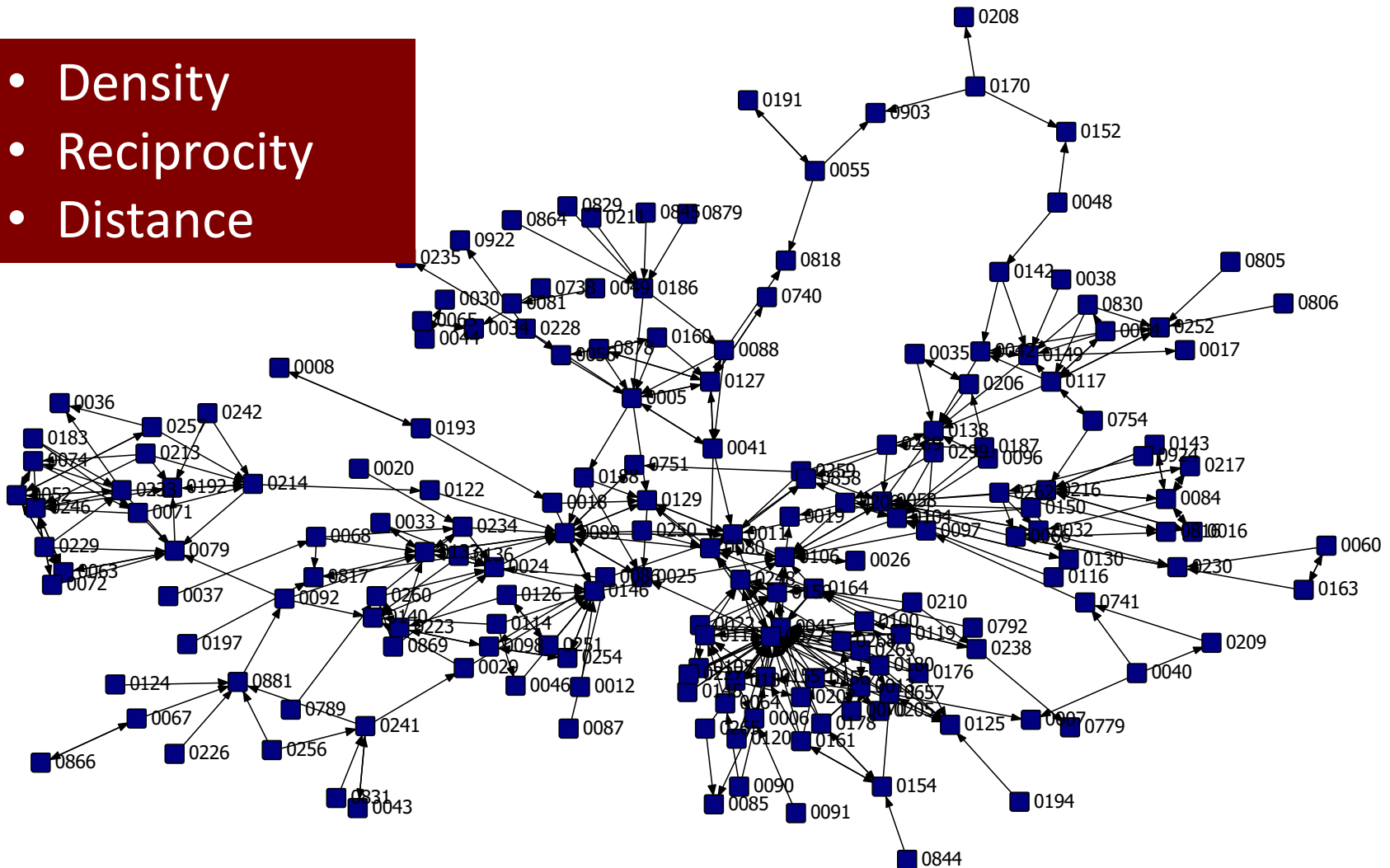
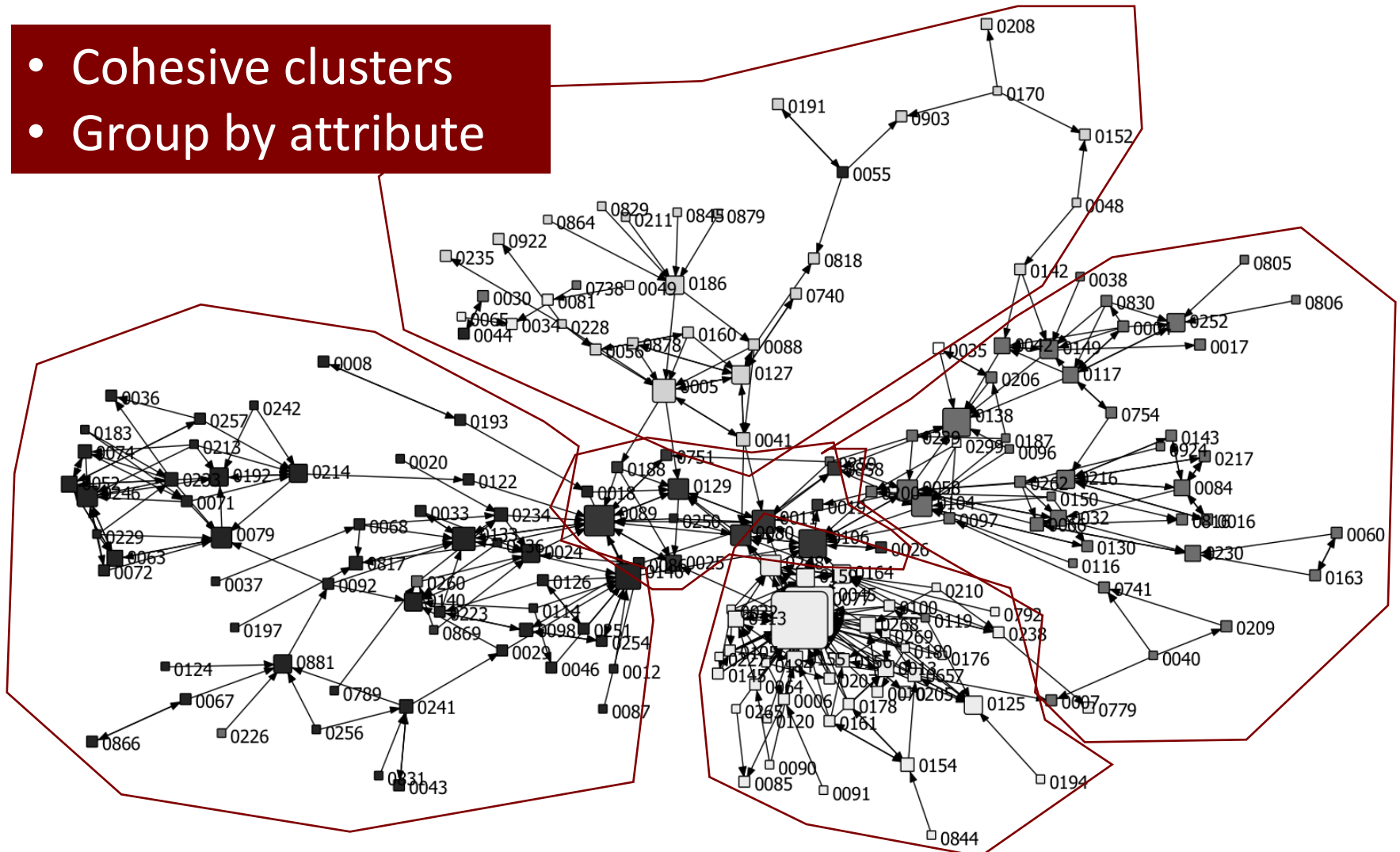# Are some nodes more prominent due to their position in the network? (e.g. centrality)
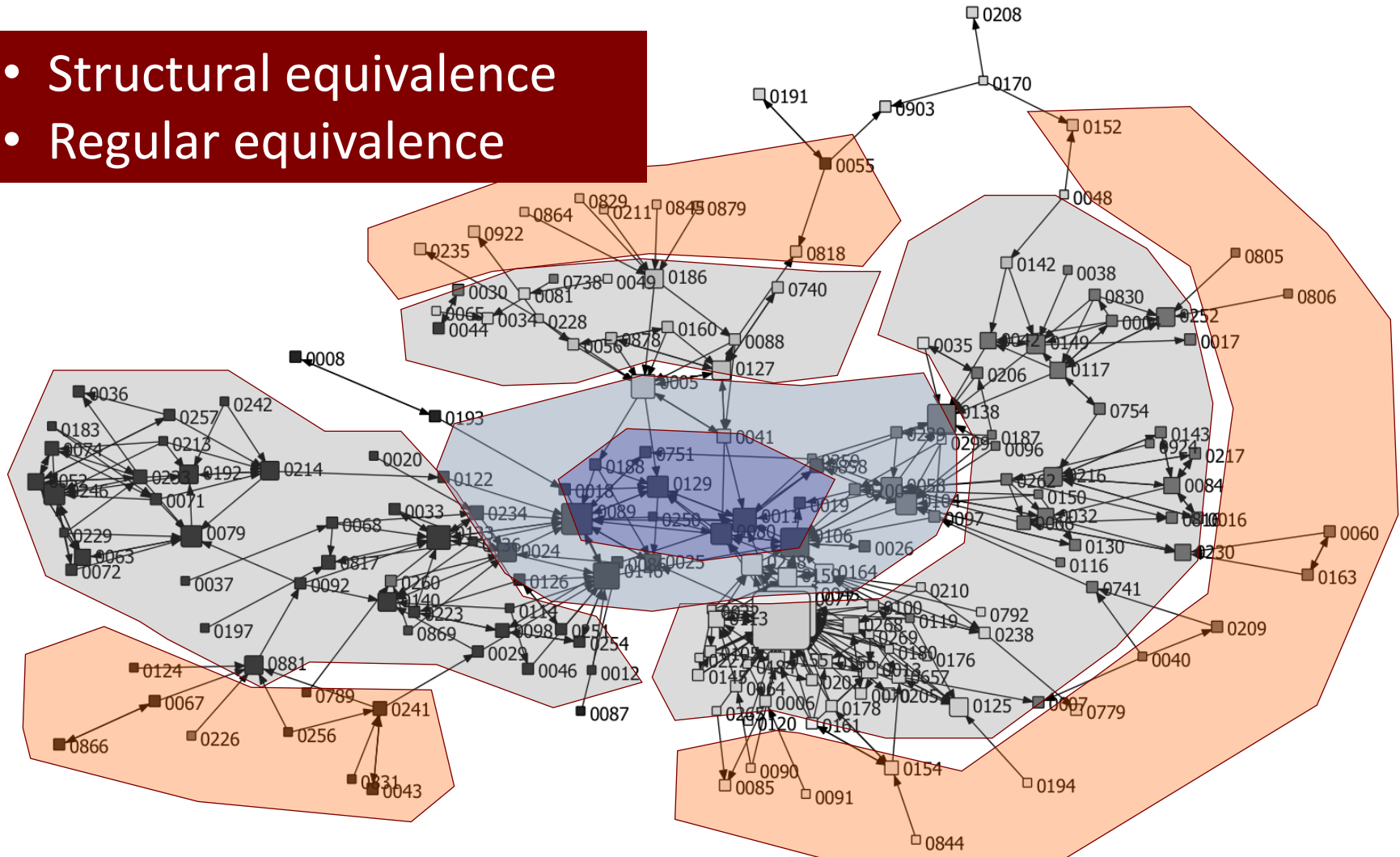
Centrality
- Degree
- Betweenness
- Closeness, etc

Is the network composed of communities?

- Cohesive clusters
- Group by attribute

Which actors have similar social positions?

- Structural equivalence
- Regular equivalence

Goals of SNA

- Descriptive/exploratory SNA
  - The network is composed of dense clusters
  - Actor x is central
- Modeling Social tendencies and trends
  - Rich get richer!
  - The friend of your friend is a potential friend!
  - Birds of a feather flock together!
- Networks as predictors of individual attributes
  - If your friend becomes overweight you are more likely to gain weight
  - Opinion leaders influence their peers' behavior
- Networks as the outcomes
  - Overweight children tend to befriend each other
  - Experts become more popular

Qualitative strand

- A theoretical sampling of respondents to the quantitative survey

- semi-structured interviews focusing on
  - how networks form the perceived role in research, expectations from the process, and relationship with the research team

  - the effect of engagement experience on motivations for network connectivity, and the themes of network transactions

Implications and impact

- Will deepen our understanding of the complex social processes that occur throughout engagement of patients in research.

- Will offer insights into how naturally occuring social networks may enhance the experiences of patients

- Will provide evidence on the effect of development of peer networks to empower patients and improve the processes of engagement

Study 2: A social network analysis of the implementation of KidFit; an innovative community-based model of care for childhood obesity

Principal investigator: Ian Zenlea

Investigators (in alphabetical order):

Dianne Fierheller, Elizabeth Mansfield, Sara Martel, Bronwyn Thompson, Reza Yousefi Nooraie

Objectives

- *KidFit* works with families across the Peel region whose children struggle with obesity-related health issues.

- identifying the health communication network of parents

- identifying the health influence network of parents

- understanding how the social networks of these families might change across time spent in a paediatric weight management program

Rationale

- obesity and obesity-related health behaviors can spread via social networks

- Traditional weight management interventions fail because they target overweight and obese individuals without consideration of social context

- Little is known about the effect of multicomponent lifestyle interventions on networks of participants and their extended social circles

- SNA has been shown to be a useful tool to support the implementation and evaluation of programs for paediatric weight management

Intervention

- *KidFit* is one of 11 hospital-based paediatric weight management programs funded by Ontario's Ministry of Health and Long-Term Care.

- Children between 2 and 17 years old are referred by a physician (typically the primary care provider) for obesity

- Patients and caregivers are enrolled in group-based programming

An ego-centric network analysis

*Each ring represents frequency of communication
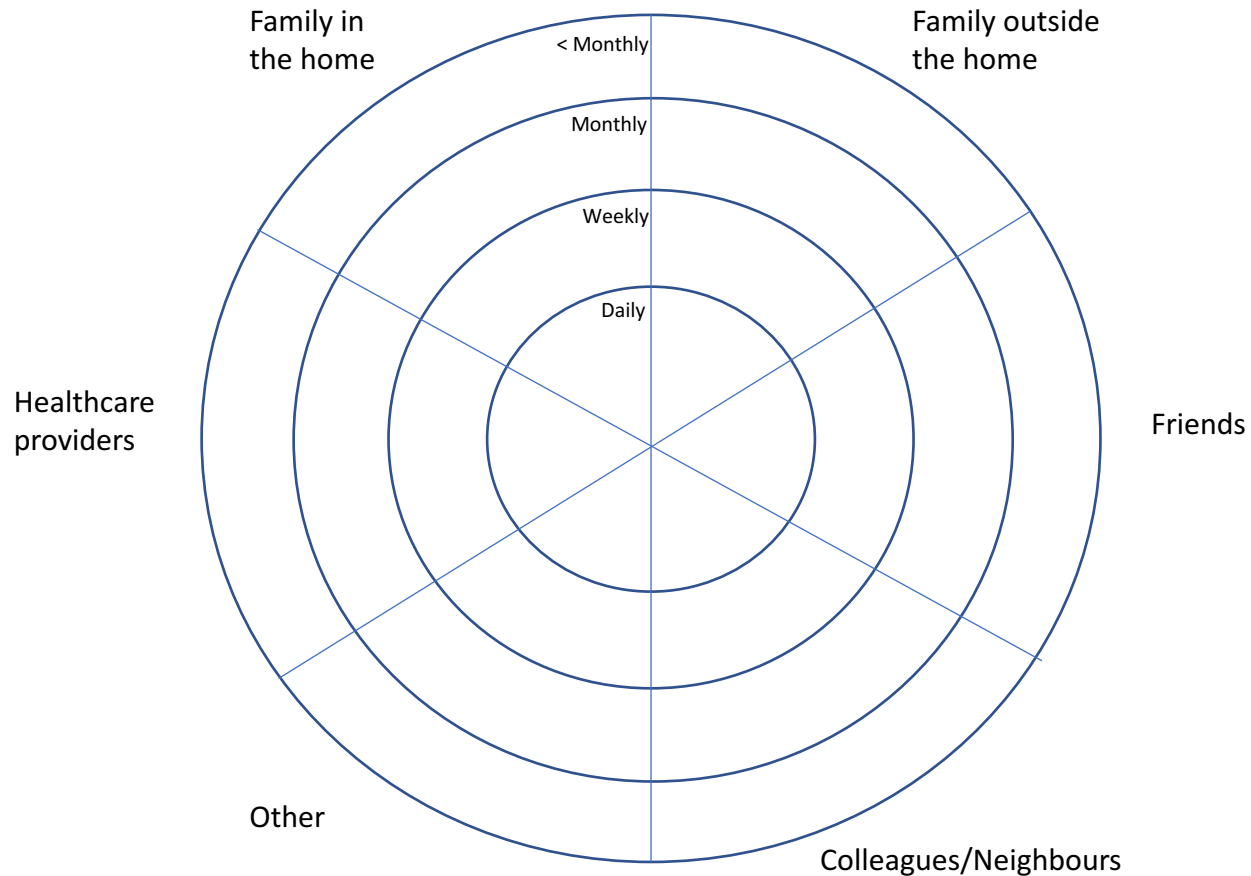
Quantitative variables collected		
Variable	**Level of analysis**	**Significance**
Number of alters, overall and in each social group (wedges)	Respondents	Network Size – quantifies the number of connections the participant has with whom they communicate regarding health
The frequency of communication	Tie (ego-alter)	The place of each alter on the concentric circles
The influence of respondent	Tie (ego-alter)	The score of respondent's influence on the beliefs and behaviors of each alter
The influence over respondent	Tie (ego-alter)	The score of alter's influence over respondent's beliefs and behaviors
Method of communication	Tie (ego-alter)	Captures how participants are communicating with each alter (face to face, phone, electronically, etc)
Membership in KidFit	Tie (ego-alter)	Whether participants are connected to other KidFit members

Hypotheses

- The group intervention will increase the density of communication network of participating parents and the strength of their ties

- The group intervention will increase the perceived influence of participants over their networks

- The group intervention will increase the frequency of health communications in participants' networks

- The group intervention will increase the size of health communication networks in participants

Study 3: Implementation of an innovation in primary care to improve access to team-based care; a social network analysis

Principal investigator: Walter Wodchis

Increasing access to team-based care

- It is difficult for primary care providers to support patients with complex care needs on their own

- Ontario has made efforts to expand collaborative team-based care in primary health care settings

- Despite evidence indicating the benefits of this care, approximately 70% of Ontarians are still managed by physicians without access to team-based care.

- The purpose of this project is to evaluate the spread of an innovation project to improve access to team-based care.

Team-based care model

- Team-based practices actively identify and recruit solo physicians from their local area.

- Examples of services include counselling, dietetic services, diabetes and other chronic disease education programs, foot care, physiotherapy, addiction services, harm reduction, settlement services, employment services, exercise, self-management and goal setting.

- A network-building intervention

- The effects on the composition and connectivity of patients' care and support network

- A longitudinal mixed methods study

Ego-centric network generators

Who are the individuals that are important in supporting you with your health care needs and well-being?

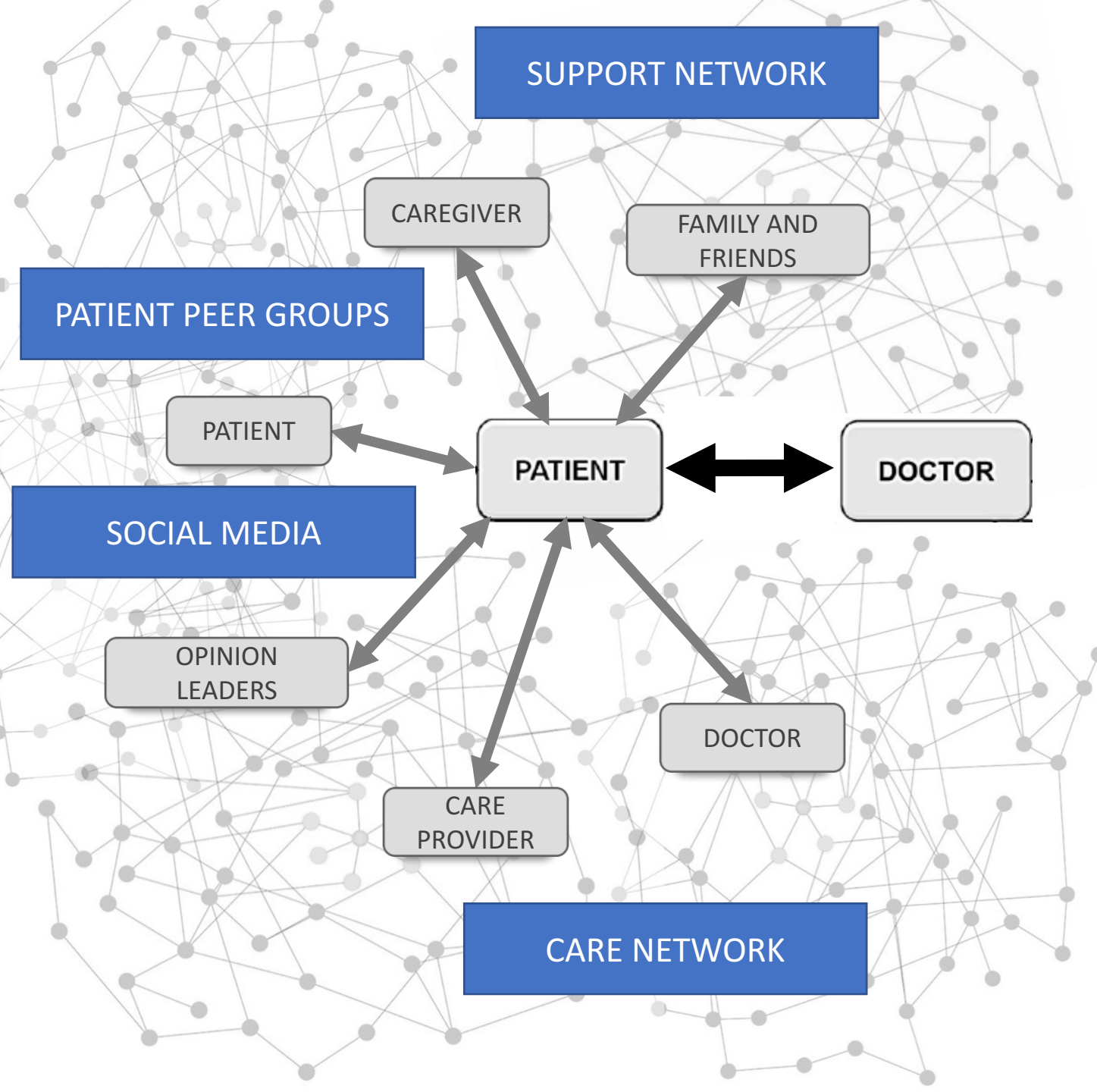| Alter's initial [e.g. My family physician, or Doctor Bob] and their relationship to ego	Frequency 1 being rarely 5 being very often	Familiarity 1 being very unfamiliar and 5 being very familiar	Ease of access 1 being very difficult a5 being very easily

Name interpreters

- **Alter attributes:**
  - What do they do for you? (For professionals: what is their role/ title, if not clear)?
  - How often do you need their help?
    - Could you rate how often you need their help on a scale of 1 to 5?
  - How familiar are they with your needs?
    - Could you rate how familiar this person is with your needs on a scale of 1 to 5?
  - How easy is it to access them or get help from them when you need it?
    - Could you rate how easily you can access this person when you need their help on a scale of 1 to 5?

- **Alter to alter relations:**
  - Do they work well together? How long have they known each other?

Hypotheses

- Increasing access to team-based care will increase the size of patients' care and support network and the quality of relations

- Increasing access to team-based care will increase patients' perception of connectivity/collaboration among medical professional actors in their care and support network

- Increasing access to team-based care will increase patients' perception of connectivity/collaboration among medical professionals and non-medical actors in their care and support network

SUPPORT NETWORK

PATIENT PEER GROUPS

SOCIAL MEDIA

CARE NETWORK

CAREGIVER

FAMILY AND FRIENDS

PATIENT
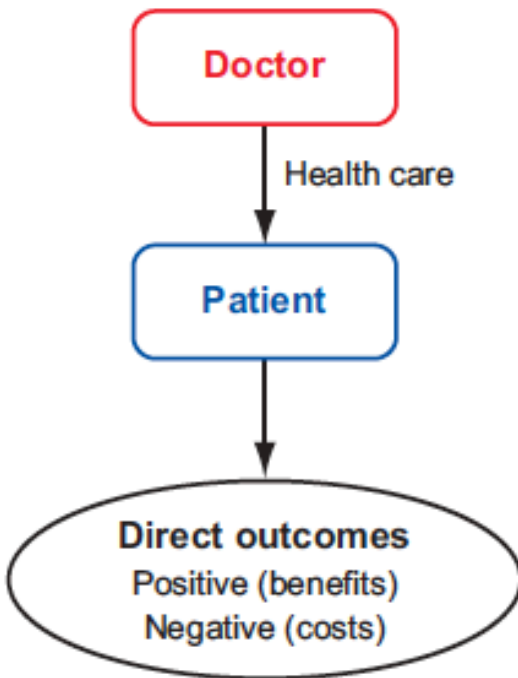
PATIENT

DOCTOR

OPINION LEADERS

CARE PROVIDER

DOCTOR

- Network as the context

- Network as a part of the intervention

- Network evaluation

Challenges
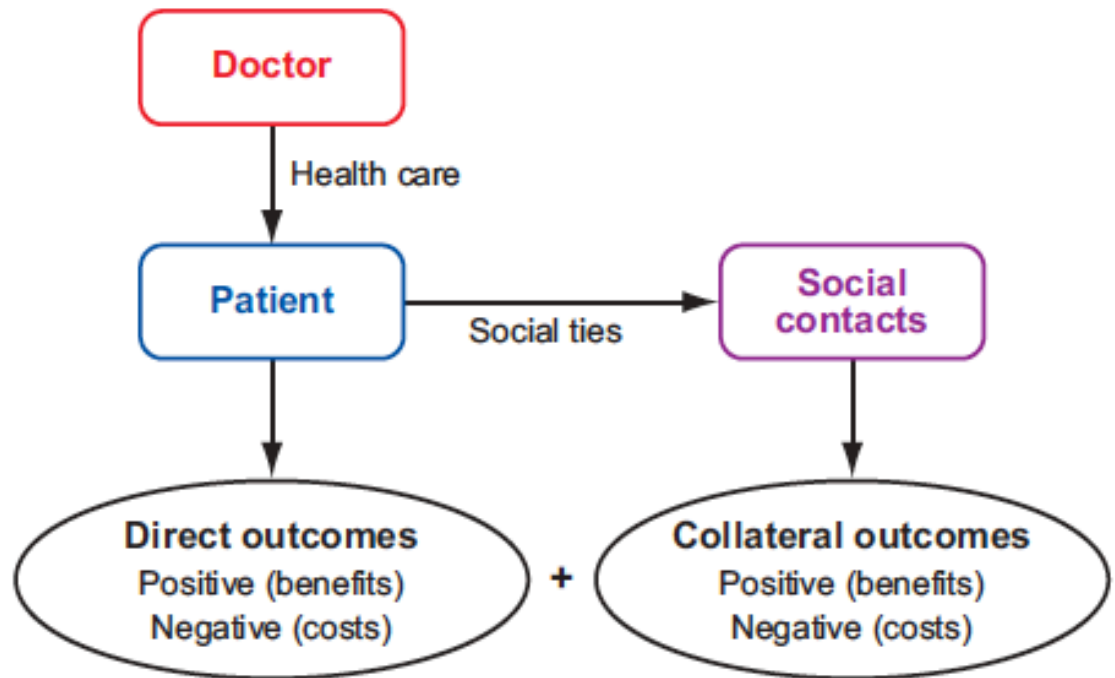
- Network analysis provides a framework, not a mechanism

- Network changes are hard to control and predict

- Data collection and analysis is complex and burdensome

- Measuring effectiveness

- Ethics

Collateral health effects are often neglected in analyses of the costs and benefits of health interventions.

Conventional perspective on medical care

Doctor
↓ Health care
Patient
↓
Direct outcomes
Positive (benefits)
Negative (costs)

Expanded perspective on medical care

Doctor
↓ Health care
Patient → Social ties → Social contacts
↓   ↓
Direct outcomes   +   Collateral outcomes
Positive (benefits)   Positive (benefits)
Negative (costs)   Negative (costs)

- treating depression in parents may increase their propensity to vaccinate their children, thereby saving children's lives Replacing a hip or pre-venting a stroke may mean that a person is better able to care for his spouse, thus improving her health.

- Delivering a weight loss intervention to one person may trigger substantial weight loss in that person's friends.

- From a societal perspective the assessment of the cost effectiveness of medical interventions might change substantially if the benefits of an intervention are seen as including the collateral positive effects and the costs as including the collateral negative effects.

- morbidity in one spouse can contribute to morbidity in the other. for example, via caregiver burden.6 Breast cancer in one woman may motivate others to whom she is connected to have mammography.7

- Exercise or smoking cessation in one person may prompt numerous others to behave similarly. Conversely, there may be epidemics of disorders such as obesity, alcoholism, suicide, or depression that might spread in a peer to peer fashion.8

- Even loose social connections can be conduits for such effects; cancer in a celebrity, for example, may motivate many people not known to the index case to undergo cancer screening or choose particular treatments.910

- Vaccinating some people in a population may cause others (for example, immunocompromised people) to become sick through the spread of the vaccine virus or, conversely, to remain well through the effect of herd immunity.