SHARED DECISION-MAKING IN ADULTS

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FER, FACAAI, FAAAAI
Editor in Chief: Current Opinion Allergy & Clinical Immunology

Personalized Medicine
Asthma & Allergy Clinic

Milano Italy
DEFINING PATIENT-CENTERED COMMUNICATION AND SHARED DECISION MAKING
3 Patient-Centered Communication and Shared Decision Making

FIGURE 3-2 People want to be involved in understanding evidence and making decisions about their care
The effectiveness of shared decision-making followed by positive reinforcement on physical disability in the long-term follow-up of patients with nonspecific low back pain in primary care: a clustered randomised controlled trial

Ariëtte R. J. Sanders, Jozien M. Bensing, Tessa Magnée, Peter Verhaak and Niek J. de Wit

BMC Family Practice 2018 19:102
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Received: 2 August 2017 | Accepted: 25 May 2018 | Published: 28 June 2018
Primary Care

Time with doctor in primary care

Malaysia 5-10 mins
Pakistan < 3 mins
UK 8 mins
Italy 8 mins
Australia 15 mins
South Africa 8 – 11 mins
Global Asthma Physician and Patient (GAPP) Survey

CANONICA G.W., BAENA CAGNANI C.  
BLAISS M., DAHL R., KALINER M. & VALOVIRTA E.

Allergy 2007
Since being diagnosed with asthma, have you ever switched from one asthma medication to another or discontinued an asthma medication because…?  Base: Currently or Has Ever Used Asthma Medication (Patients)
Who Initiates Discussion About Asthma Medication Side Effects?

- 60% Me
- 40% Doctor Or healthcare provider
- 2% do not discuss side effects

21% Patient

Canonica et al., Allergy 2007
Patients and Physicians Disagree on Content of Education Provided and Received

Patients perceive that only 25% of office visit time is devoted to asthma education

% of Respondents

Does your doctor or other healthcare professional in his or her office discuss any of the following with you?
Base: All Respondents (Patients)

Do you regularly discuss the following with your asthma patients? Base: All Respondents (Physicians)

Canonica et al., Allergy 2007
### Treatment Compliance Increases with Increased Patient Education

<table>
<thead>
<tr>
<th>Patient Treatment Compliance</th>
<th>Amount of time spent on patient education</th>
</tr>
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<tbody>
<tr>
<td>&lt; 51%</td>
<td>15%</td>
</tr>
<tr>
<td>51-80%</td>
<td>27%</td>
</tr>
<tr>
<td>81-99%</td>
<td>29%</td>
</tr>
<tr>
<td>100%</td>
<td>30%</td>
</tr>
</tbody>
</table>

**Increase in Compliance (%)**

Canonica et al., Allergy 2007
3 Patient-Centered Communication and Shared Decision Making

![Diagram of Patient-Centered Care]

**FIGURE 3-1** Model of patient-centered care
3 Patient-Centered Communication and Shared Decision Making

- patient education and empowerment;
- patient-centered communication, which involves the patient, family, and friends; explains treatment options; and includes patients in treatment decisions to reflect patients' values, preferences, and needs;
- coordination and integration of care; and
- provision of emotional support as needed, such as relieving fear and anxiety and addressing mental health issues.

<table>
<thead>
<tr>
<th>Function</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Fostering</td>
<td>Developing a patient-clinician relationship that is characterized by trust and patient-centered communication and shared decision making. This involves patient-centered roles, as well as clinician self-awareness and professional support, guidance, and understanding.</td>
</tr>
<tr>
<td>Healing Relationships</td>
<td>The cancer care team should address patients' emotional needs. Communication between patients and clinicians should occur through the ask-tell-ask method, which emphasizes prioritizing clinician training in communication. The exchange includes provision of accurate prognostic information and treatment options, realistic responses to treatment, and the cost of cancer care to inform patients' decisions.</td>
</tr>
<tr>
<td>Exchanging Information</td>
<td>The cancer care team should recognize and respond to patients' emotions, expressing understanding, legitimizing feelings, and providing empathy. This includes the development of a psychosocial care plan and linking patients to services they need.</td>
</tr>
<tr>
<td>Responding to Emotions</td>
<td>The cancer care team should recognize and respond to patients' emotions, expressing understanding, legitimizing feelings, and providing empathy. This includes the development of a psychosocial care plan and linking patients to services they need.</td>
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</tbody>
</table>
Strategies for integrating personalized medicine into healthcare practice

For reprint orders, please contact: reprints@futuremedicine.com
Progression of strategies by area of need for the traditional medical practice to personalised medicine
Implementing shared decision-making: consider all the consequences

Glyn Elwyn, Dominick L. Frosch, and Sarah Kobrin

Conclusion: We suggest that a broader conceptualization and measurement of shared decision-making would provide a more substantive evidence base to guide implementation. We outline a framework which illustrates a hypothesized set of proximal, distal, and distant consequences that might occur if collaboration and deliberation could be achieved routinely, proposing that well-informed preference-based patient decisions might lead to safer, more cost-effective healthcare, which in turn might result in reduced utilization rates and improved health outcomes.
Fig. 1 The potential consequences of collaborative deliberation

- **Collaborative Deliberation**: Collaborative deliberation, achieved consistently across clinical teams, results in well-informed patients, and in preference-based decisions.
- **Proximal effects**: Informed patient preference-based decisions result in safer, cost-effective, patient-aligned healthcare.
- **Distal effects**: Patient-aligned healthcare results in improvements in utilization rates, resource use, planning processes, and improved health outcomes.
- **Positive System Feedback**
Table 2  Examples of emerging research questions

Proximal consequences

- Does the preferred patient role in decision-making lead to different outcomes?
- What characteristics of patients, process, clinicians, settings and decisions moderate this relationship?
- Is there sufficient clarity about proximal outcomes and how they are measured?
- Do we have robust concepts as the basis for measuring decision processes, decision outcomes (confidence, conflict, regret etc), and to what degree are these mediators for distal outcomes such as treatment choice, adherence to chosen treatment, and other patient determined and patient-reported outcomes.
- Models could be proposed and evaluated in an effort to elucidate the mediation path from a shared decision making process to a selected set of consequences.

Distal topics

- Do people who participate in shared decision making prior to an invasive procedure experience less distress in response to treatment side effects or adverse events than those who did not participate in shared decision making?
- Is the distress mediated by more realistic expectations resulting from the shared decision making?

Distant topics

- How would resource use be affected by the implementation of shared decision making in different types of healthcare delivery settings?
- How would implementation of shared decision making prior to specific procedures affect rates of malpractice investigations concerning such procedures?
- How might these effects vary by type of healthcare delivery setting?
Research ideas
To address these issues, we propose a range of research ideas:

- Recruit and study health systems that are willing to invest in shared decision-making, at clinician, clinical team, managerial, and system levels. Ensure fidelity by measuring interactional processes at team levels. Baseline measures of team functioning, staff turnover, intervention rates, and other quality metrics would be available for comparison using time series analyses. Although some of the postulated longer term consequences might take a number of years, distal consequences might be evident sooner, such as patient-centered metrics, complaint levels, staff turnover, and team performance levels.

- Address questions at the level of teams in organizations, recognizing that high functioning teams might achieve fidelity in accomplishing new processes rapidly, and therefore exhibit the proposed consequences in less time. A range of experimental or observational designs could be used, comparing teams at different levels of motivation and performance.

- As noted, selecting healthcare systems already committed to higher quality at lower cost will be critical. Fortunately, multiple examples of such organizations are emerging as healthcare systems strive to become more cost-effective. In the USA, health reform efforts have introduced the concept of Accountable Care Organizations that are not based on fee-for-service payment models. These systems would be good settings for future evaluations. Healthcare providers in single-payer systems are also well-placed to test the effect of consistently accomplished shared decision making, provided they address the profit-driven influences of payer and provider separation. The implementation challenge is to ensure that the organizational governance and reward system is aligned with delivering consistent levels of collaborative deliberation at the front line rather than by the volume of work achieved. Research that monitors the alignment or otherwise of incentives, from the board room, to clinical management, that directly or indirectly influence front line clinicians would help illuminate the reported tensions felt by the clinical workforce. Research to compare different incentive frameworks, intrinsic and extrinsic, would be helpful.
Conclusions

Shared decision-making has been welcomed by policymakers worldwide—it resonates and supports the ethical imperative of respect for patient autonomy and engagement [40]. Yet, as we hope this article shows, the potential enduring benefits and unintended consequences of consistently accomplished collaboration and deliberation have not been sufficiently laid out and, therefore, not investigated.
Introduction to P4 Medicine
What is P4 Medicine?

P4 Medicine is a plan to radically improve the quality of human life via biotechnology.

P4 Medicine is a term coined by biologist Leroy Hood, and is short for “Predictive, Preventive, Personalized, and Participatory Medicine.” The premise of P4 Medicine is that, over the next 20 years, medical practice will be revolutionized by biotechnology, to manage a person’s health, instead of manage a patient’s disease.
From systems biology to P4 medicine: applications in respiratory medicine

Guillaume Noell¹,², Rosa Faner¹,² and Alvar Agustí¹,²,³

Number 4 in the Series “Personalised medicine in respiratory diseases”
Edited by Renaud Louis and Nicolas Roche

Affiliations: ¹Institut d’Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS), Barcelona, Spain. ²CIBER Enfermedades Respiratorias (CIBERES), Barcelona, Spain. ³Respiratory Institute, Hospital Clínic, Universitat de Barcelona, Barcelona, Spain.

Correspondence: Alvar Agustí, Respiratory Institute, Hospital Clínic, Villarroel 170, 08036 Barcelona, Spain. E-mail: AAGUSTI@clinic.cat
FIGURE 1 Multilevel layers of biological, environmental and social information ideally integrated in systems biomedicine approaches. For further explanations, see text. Reproduced and modified from [2] with permission.
<table>
<thead>
<tr>
<th>Table 1: Common omics data types</th>
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<tbody>
<tr>
<td><strong>Assay</strong></td>
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<tr>
<td>Genomics</td>
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<td>Transcriptomics</td>
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<td>Proteomics</td>
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<td>Metabolomics</td>
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<tr>
<td>Epigenomics</td>
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<tr>
<td>Microbiomics</td>
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</tbody>
</table>

SNP: single nucleotide polymorphism; GWAS: genome-wide association study; MS: mass spectrometry.
The Need for Humanomics in the Era of Genomics and the Challenge of Chronic Disease Management

J. Mark FitzGerald, MD
Iraj Poureslami, PhD
Vancouver, BC, Canada

Personomics

It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.

Sir William Osler
P4 Medicine: Personalized, Predictive, Preventive, Participatory

A Change of View that Changes Everything

Leroy E. Hood
Institute for Systems Biology

David J. Galas
Battelle Memorial Institute

Version 6: December 12, 2008
Asthma: personalized and precision medicine

Giorgio W. Canonica, Matteo Ferrando, Ilaria Baiardini, Francesca Puggioni, Francesca Racca, Giovanni Passalacqua, and Enrico Heffler

Canonica et al., COAI Dec 2017
**HUMANOMICS**

**Correct Approach to Patient**

**PERSONOMICS**

**P4-PARTECIPATORY MEDICINE**

**BEST PATIENT’s EVALUATION**

**HUMANOMICS**

*Fig.1 Canonica et al., COAI Dec 2017*
**Steps Forward to Best Treatment**

- Current Disease Management
- OMIC Sciences
- Personalized Medicine
- Precision Medicine
- Systems Biology
- P4-Participatory Med. & Choosing Wisely

**Fig. 2**

Canonica et al., COAI Dec 2017
P4 Medicine
Predictive
Preventive
Personalized
Participatory
A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory

Leroy Hood\(^1\) and Mauricio Flores\(^2\)

\(^1\) Institute for Systems Biology, 401 N. Terry Ave, Seattle, WA 98121, USA
\(^2\) P4 Medicine Institute, 401 N. Terry Ave, Seattle, WA 98121, USA
In 10 years a virtual cloud of billions of data points will surround each patient. These data will be of many different types and, accordingly, multistage. The challenge will be to convert these data into simple hypotheses about health and disease for the individual.
NETWORK of NETWORKS

**Figure 2**
A figure depicting the ‘network of networks’ that specifies the nature of some of the integrated networks that specify normal biology and disease. The genetic, molecular, cellular, organ and individual networks are represented—and they represent a fully integrated network of networks. Networks are powerful tools for integrating and modeling biological data. Networks also provide a powerful means for dealing with signal to noise problems.
The 'holy trinity of biology' where biology drives technology drives computational/mathematical tools. Practicing this ideally requires a cross-disciplinary environment where scientists of many different disciplines (see lower right hand side of figure) learn to speak the languages of the other scientists and learn to work together in teams. When the holy trinity is practiced effectively enormous amounts of biological information can be generated rapidly.
A schematic of the prion accumulation and replication network in the prion-induced mouse neurodegenerative disease. The red indicates transcript levels that have been increased in the brains from prion-infected animals as compared with normal control brains. The yellow indicated transcripts that are the same in control and diseased animals. The three panels represent the network at 2, 12 and 20 weeks in animals that live about 22 weeks with this disease. The disease-perturbed networks appear about eight weeks before the clinical signs appear in these animals.
Family with congenital heart disease caused by a GATA4 mutation.
A diagram of organ-specific blood fingerprints (collections of organ-specific proteins) from the brain and the liver. For example, in a normal brain, each of the proteins in the brain-specific blood fingerprint will have one set of levels. In a diseased brain, the proteins whose cognate networks have become disease-perturbed will change their levels. Because each disease leads to distinct combinations of disease-perturbed networks – an analysis of the brain-specific protein fingerprints can distinguish healthy from diseased brains, and if diseased can stratify (e.g. distinguish from one another) the distinct types of brain diseases. Thus organ-specific brain fingerprints can provide early detection, a stratification of different types of disease and the ability to follow the progression of the disease (not shown).
<table>
<thead>
<tr>
<th>Reactive medicine – evidence-based medicine</th>
<th>Proactive P4 medicine</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reactive</strong>-respond after a patient is sick (symptom based)</td>
<td><strong>Proactive</strong>-responds before a patient is sick (based on pre-symptomatic markers)</td>
</tr>
<tr>
<td>Disease-treatment system</td>
<td>Wellness-maintenance system</td>
</tr>
<tr>
<td>Few measurements</td>
<td>Many measurements, including complete genome sequencing, high-parameter blood diagnostics, many longitudinal omics measurements</td>
</tr>
<tr>
<td>Disease-centric, with standard of care associated with population-based disease diagnosis</td>
<td>Individual-centric, with standard of care tailored more fully to multiple measurements on the individual</td>
</tr>
<tr>
<td>Records not highly linked</td>
<td>Deeply integrated data that can be mined for continued improvement of healthcare strategies</td>
</tr>
<tr>
<td>Large-scale diffusion of medical information mediated mostly through physicians alone</td>
<td>Social networking of patients to enhanced shared experiences and diffusion of knowledge in consultation with their physicians</td>
</tr>
<tr>
<td>Drugs tested against large populations – 10s of thousands to develop statistics for FDA</td>
<td>Stratification of disease populations into small groups, 50 or so, that can be effectively treated to achieve FDA approval</td>
</tr>
<tr>
<td>Science based healthcare takes place almost entirely in clinics and hospitals</td>
<td>Science based healthcare takes place in the home as well as the clinic as networked and activated healthcare consumers use the information made available from systems biology and wireless measuring devices to do a better job of managing their health</td>
</tr>
<tr>
<td>Discovery science and medicine are largely separate spheres of activity which communicate primarily through publication of articles in peer reviewed journals</td>
<td>Discovery science and the practice of medicine are integrated through digital networks and heterogeneous databases that capture data from every clinical encounter for discovery purposes and quickly and efficiently distribute information about stratified diseases and populations to physicians on an ongoing basis</td>
</tr>
</tbody>
</table>
TABLE 2

A summary of the principal opportunities that P4 medicine will bring to medicine and healthcare

| Systems approaches provide fundamental new insights into disease mechanisms |
| The human genome through actionable variant genes provides a means to begin optimizing human health and deal with disease |
| Blood as a window into health and disease – disease diagnostics, drug toxicity assessment, wellness assessment, among others |
| Stratification of diseases into their subtypes for a proper impedance match against a patient's disease and discovery of the proper drug |
| Assessment of multi-organ response in a disease |
| New approach to drug target discovery – re-engineering disease-perturbed networks to behave normally with drugs |
| Digitization of individual human parameters offers the opportunity for focusing on wellness, optimizing patient treatments and mining for the predictive medicine of the future create metrics for assessing and optimizing wellness |
### TABLE 2

**A summary of the principal opportunities that P4 medicine will bring to medicine and healthcare**

- Systems approaches provide fundamental new insights into disease mechanisms
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- Stratification of diseases into their subtypes for a proper impedance match against a patient’s disease and discovery of the proper drug
- Assessment of multi-organ response in a disease
- New approach to drug target discovery – re-engineering disease-perturbed networks to behave normally with drugs
- Digitization of individual human parameters offers the opportunity for focusing on wellness, optimizing patient treatments and mining for the predictive medicine of the future create metrics for assessing and optimizing wellness
Systems biology

• Systems biology – holistic, global and integrative in approach – has given rise to systems medicine, a systems approach to health and disease.

• Hood & Flores, New Biotechnology 2012
Systems medicine promises

• Systems medicine promises to
• (1) provide deep insights into disease mechanisms,
• (2) make blood a diagnostic window for viewing health and disease for the individual,
• (3) stratify complex diseases into their distinct subtypes for a impedance match against proper drugs,
• (4) provide new approaches to drug target discovery and
• (5) generate metrics for assessing wellness
**P4 medicine, the clinical face of systems medicine**

- P4 medicine, the clinical face of systems medicine, has **two major objectives**: to quantify wellness and to demystify disease.
FIGURE 7
A schematic representation of the two major objectives of P4 medicine: quantifying wellness and demystifying disease.
P4 medicine, the clinical face of systems medicine

- P4 medicine, the clinical face of systems medicine, has two major objectives: to quantify wellness and to demystify disease.
- Patients and consumers will be a major driver in the realization of P4 medicine through their participation in medically oriented social networks directed at improving their own healthcare.
- P4 medicine has striking implications for society – including the ability to turn around the ever-escalating costs of healthcare.
FIGURE 8
A network depicting the interacting components of the healthcare system indicating the dominant role that patients will have in advancing P4 medicine through their consumer-driven social networks. Networks allow one to organize and model data and are important in dealing with the signal to noise problem of large data sets.
KEY MESSAGE

• Strategic partnerships of a variety of types will be necessary to bring P4 medicine to patients.
A Charter to Improve Patient Care in Severe Asthma

Andrew Menzies-Gow · G-Walter Canonica · Tonya A. Winders ·
Jaime Correia de Sousa · John W. Upham · Antje-Henriette Hinke-Wagner
• New projects should be instrumental to provide answers to these points
Severe Asthma Center Networking

**FIGURE 3.** Severe Asthma Center Networking would ameliorate the exchange of data and information on severe asthmatic patients.

DATA ANALYSIS will also include all the real life data collected. It will allow comparisons and suggestions on the best performance(s) in clinical practice.
TAKE HOME MESSAGES
P4 Medicine Needs P4 Education

Author(s): Alfredo Cesario, Charles Auffray, Patrizia Russo, Leroy Hood.

Journal Name: Current Pharmaceutical Design

Volume 20 , Issue 38 , 2014  
DOI : 10.2174/1381612820666140314145
445
When Osler implored physicians to focus on the patient, he almost certainly was not thinking only about human biology. Personomics must take its place beside genomics, proteomics, pharmacogenomics, metabolomics, and epigenomics if we are to truly realize the potential of personalized medicine and not simply some aspects of it, and if we are to prepare our students and residents to deliver individualized health care when they enter the practice of medicine.