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SHARED DECISION-MAKING IN ADULTS

Prof. **Giorgio Walter Canonica**

FERS, FACAAI, FAAAAI

Editor in Chief : Current Opinion Allergy & Clinical Immunology

Personalized Medicine
Asthma & Allergy Clinic

HUMANITAS
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Milano Italy

DEFINING PATIENT-CENTERED COMMUNICATION AND SHARED DECISION MAKING



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3 Patient-Centered Communication and Shared Decision Making

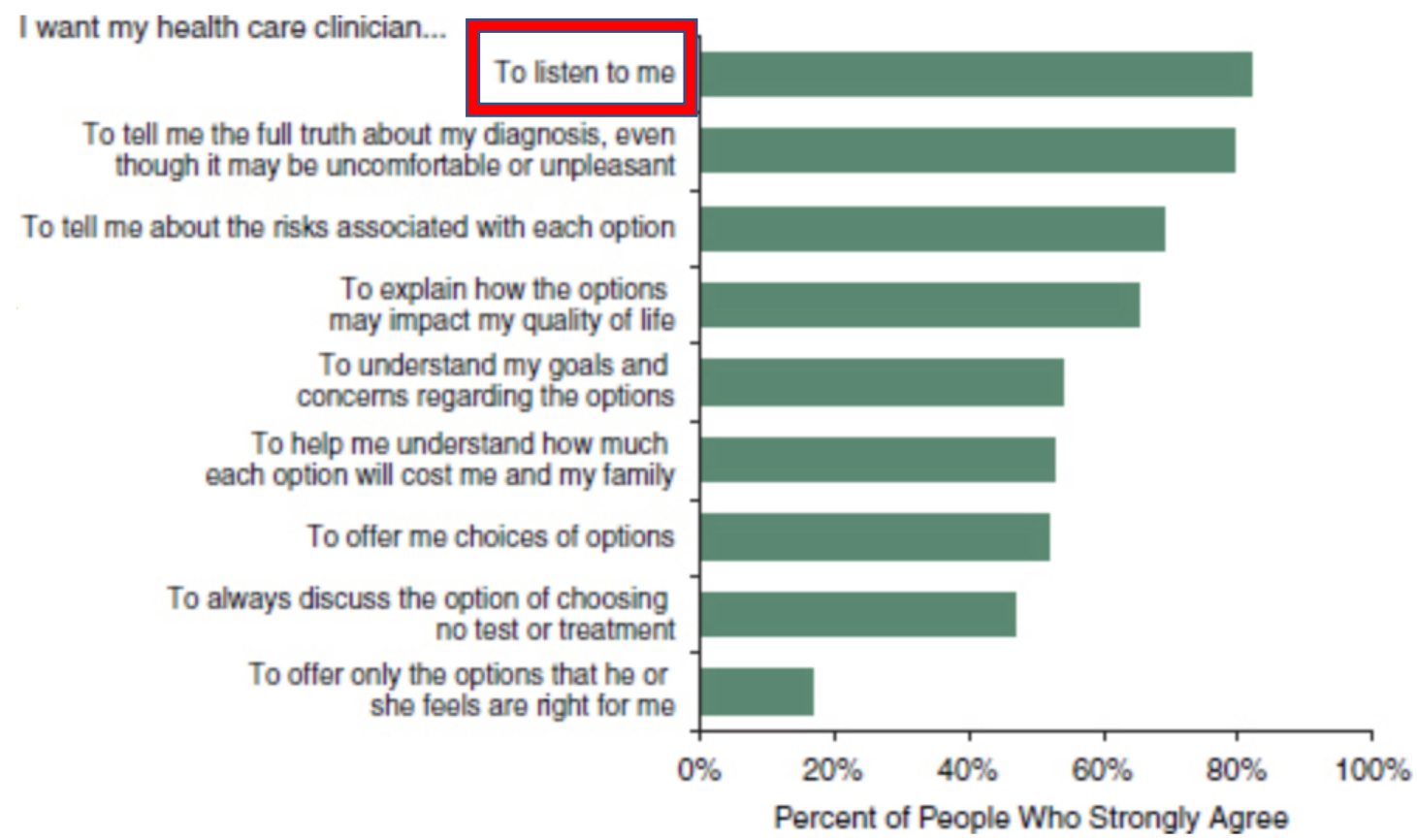


FIGURE 3-2 People want to be involved in understanding evidence and making decisions about their care

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

<https://doi.org/10.1186/s12875-018-0776-8> | © The Author(s). 2018

Received: 2 August 2017 | Accepted: 25 May 2018 | Published: 28 June 2018

Primary Care

Time with doctor in primary care

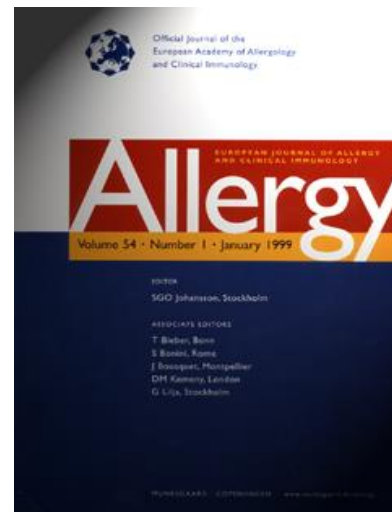


Malaysia	5-10 mins
Pakistan	< 3 mins
UK	8 mins
Italy	8 mins
Australia	15 mins
South Africa	8 – 11 mins



Global Asthma Physician and Patient (GAPP) Survey

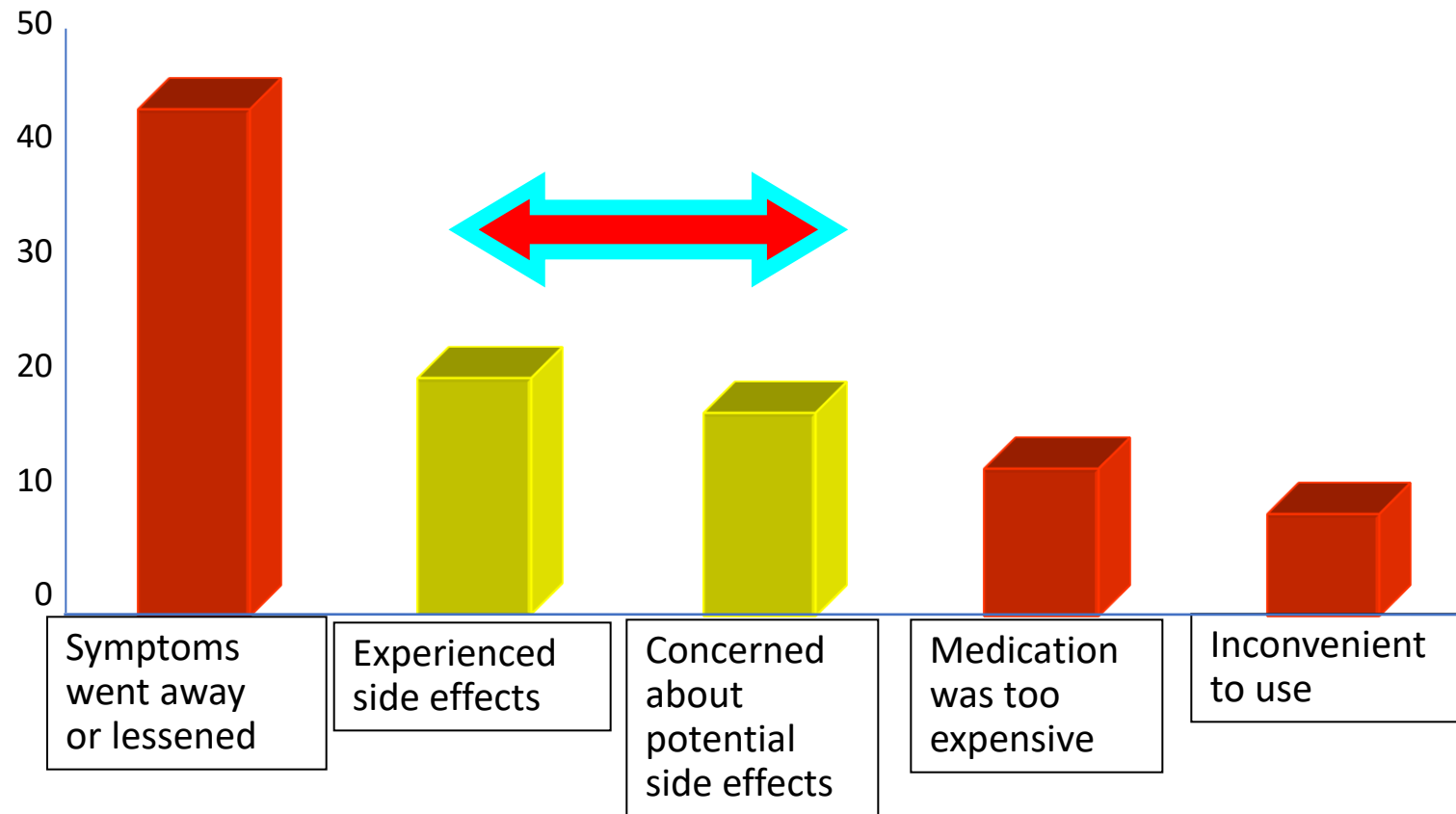
CANONICA G.W., BAENA CAGNANI C.
BLAISS M., DAHL R., KALINER M. & VALOVIRTA E.



Allergy 2007

Reasons Patients Switched/Discontinued Asthma Medications

Side Effects Lead to Patients Switching or Discontinuing Treatment



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)

Allergy 2007

Who Initiates Discussion About Asthma Medication Side Effects?

40%
Doctor
Or healthcare
provider



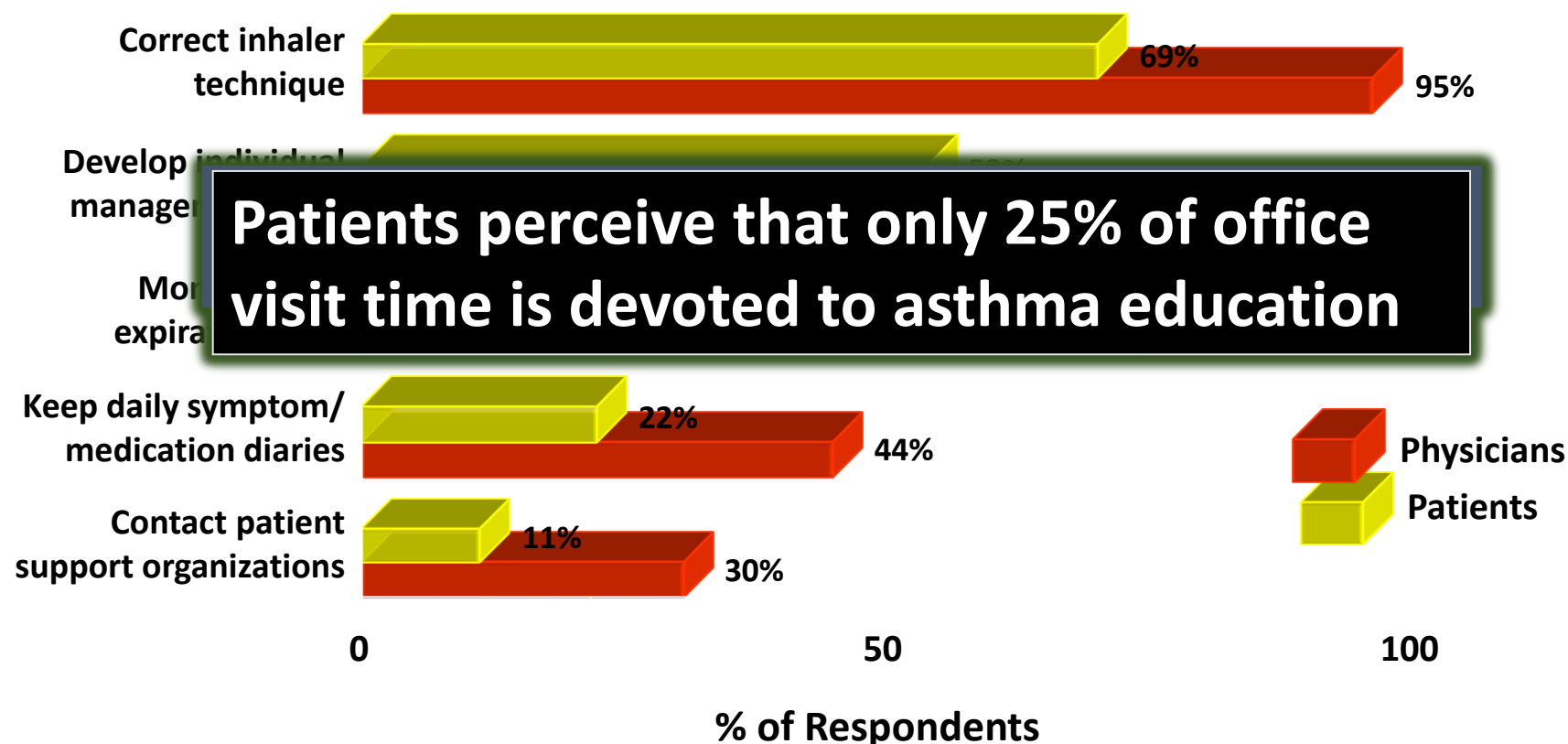
21%
Patient



2% do not
discuss
side effects

Canonica et al., Allergy 2007

Patients and Physicians Disagree on Content of Education Provided and Received

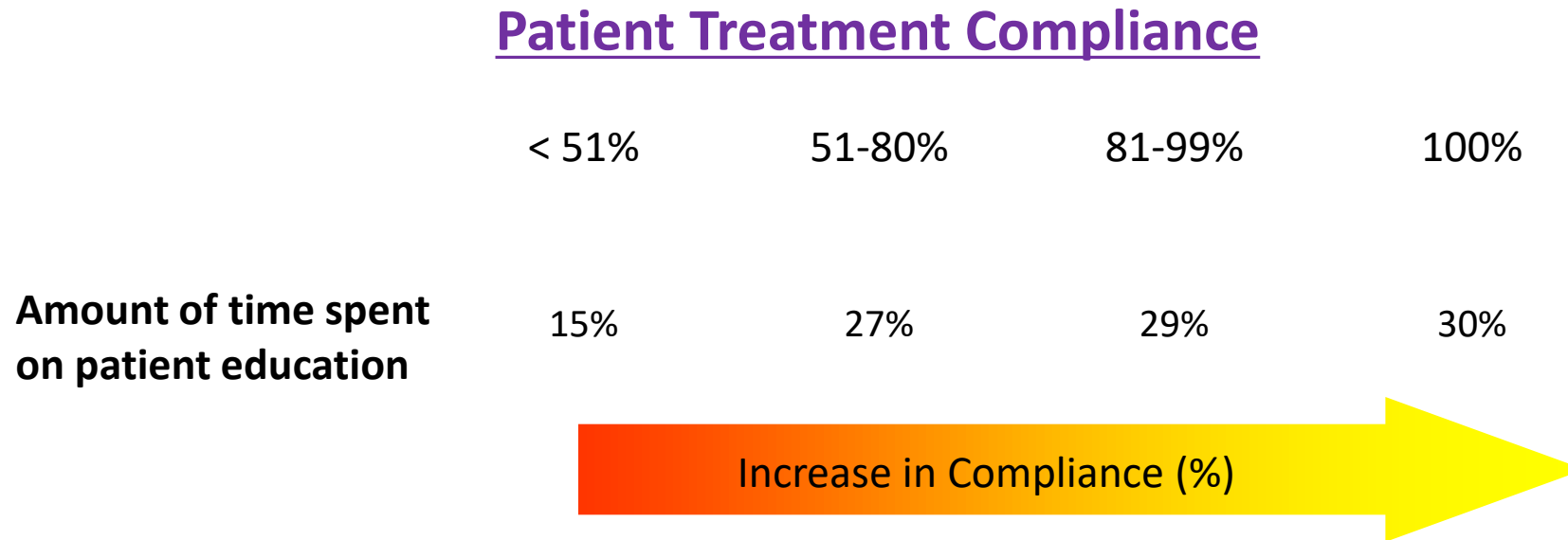


Does your doctor or other healthcare professional in his or her office discuss any of the following with you?

Base: All Respondents (Patients)

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

Treatment Compliance Increases with Increased Patient Education





Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis.

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3 Patient-Centered Communication and Shared Decision Making

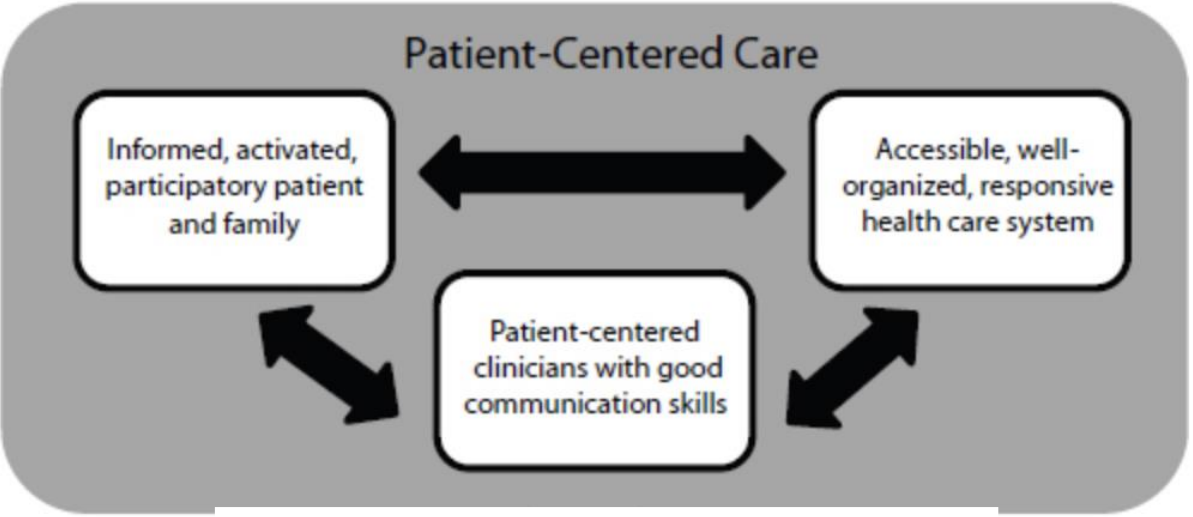


FIGURE 3-1 Model of patient-centered care



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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 3-1 Important Functions of Patient-Clinician Communication

Function	Description
Fostering Healing Relationships	Developing a patient-clinician relationship that is characterized by trust and patient-centered communication and shared decision making. This involves defining patient and clinician roles, as well as clinician self-awareness and professional support, guidance, and understanding.
Exchanging Information	The cancer care team should ascertain patients' informational needs. Communication with patients can be facilitated through the ask-tell-ask method, an approach developed by prioritizing clinician training in communication. The exchange includes the provision of accurate prognostic information and treatment options, realistic expectations of response to treatment, and the cost of cancer care to inform patients' decisions.
Responding to Emotions	The cancer care team should recognize and respond to patients' emotions, expressing understanding, legitimizing feelings, and providing empathy and support. This includes the development of a psychosocial care plan and linking patients to resources. Patients who experience high levels of emotional distress, anxiety, and depression may benefit from additional support.



Daryl E Pritchard^{*,1}, Franziska Moeckel², Mary Susan Villa³, Laura T Housman^{4,5}, Catherine A McCarty⁶ & Howard L McLeod⁷

Research Article

For reprint orders, please contact: reprints@futuremedicine.com

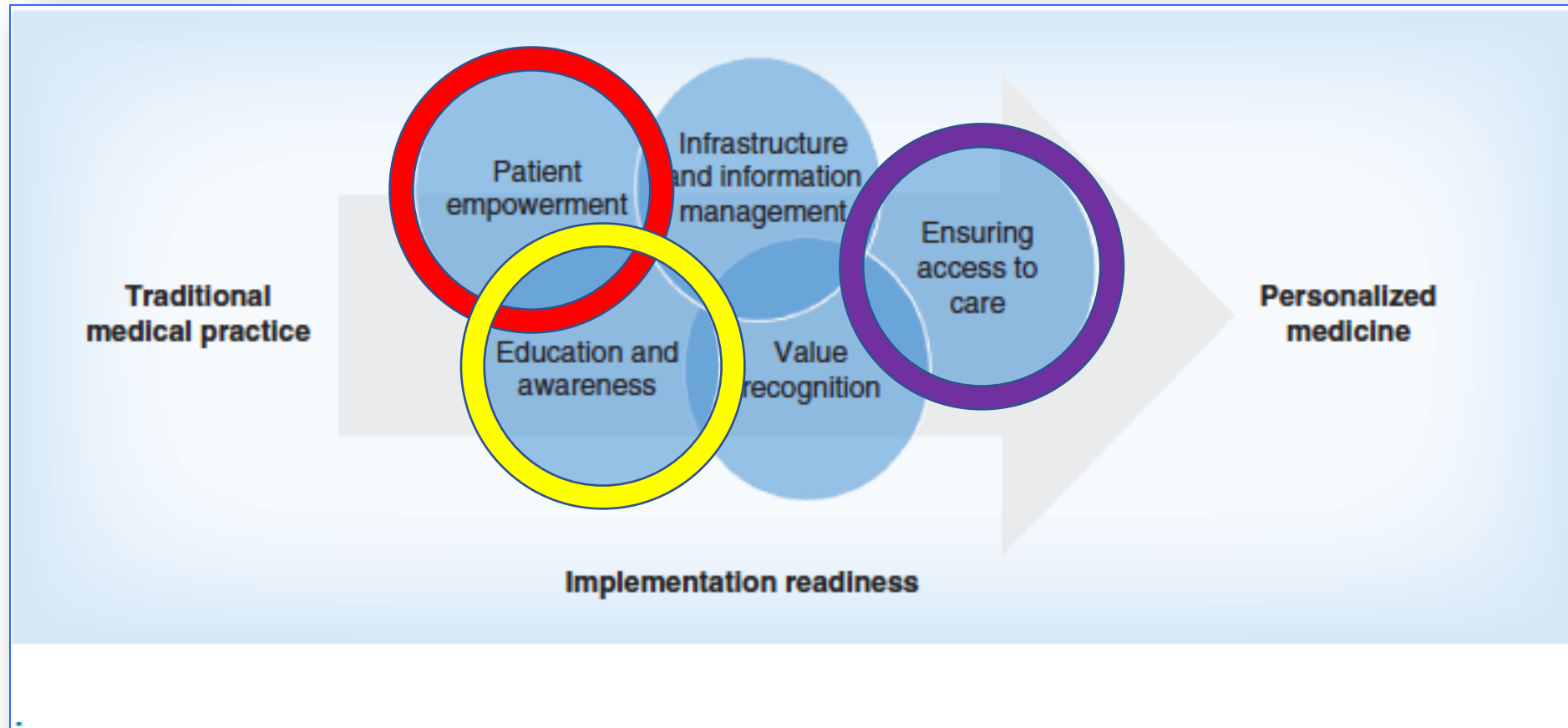
Strategies for integrating personalized medicine into healthcare practice

Personalized Medicine





Progression of strategies by area of need for the traditional medical practice to personalised medicine



DEBATE

Open Access



Implementing shared decision-making: consider all the consequences

Glyn Elwyn^{1*} , Dominick L. Frosch^{2,3} and Sarah Kobrin⁴

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.

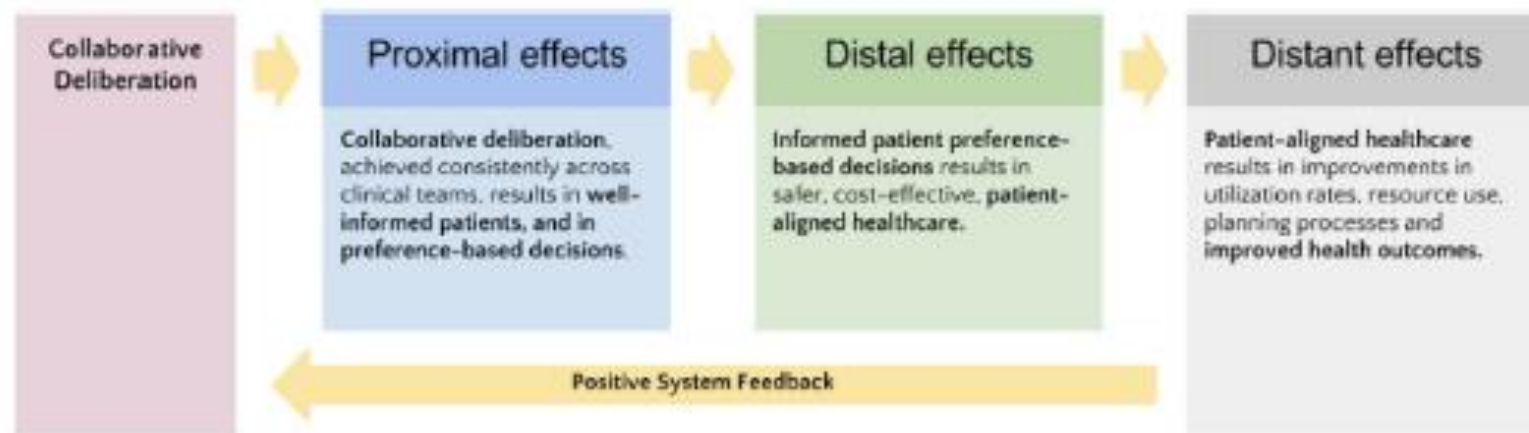


Fig. 1 The potential consequences of collaborative deliberation

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 *process*, 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 policy makers world wide—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



P 4 M E D I C I N E
PERSONAL WELLNESS FOR EVERYONE



- ***Predictive***
- ***Preventive***
- ***Personalized***
- ***Participatory***

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.



CrossMark

From systems biology to P4 medicine: applications in respiratory medicine

Guillaume Noell^{1,2}, Rosa Faner^{1,2} and Alvar Agustí^{1,2,3}

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

Affiliations: ¹Institut d'Investigacions Biomediques 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

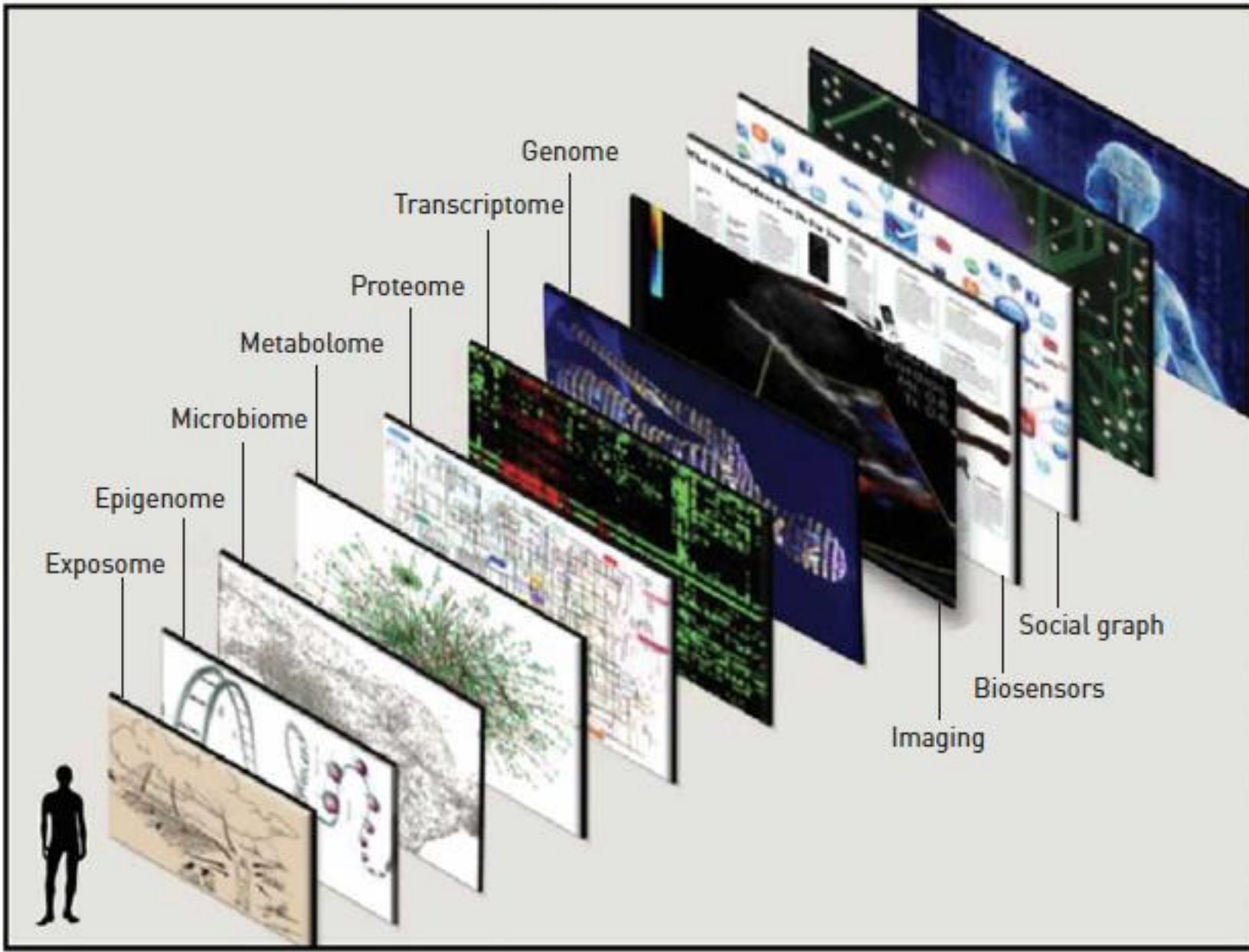


FIGURE 1 Multilevel layers of biological, environmental and social information ideally integrated in systems biomedicine approaches. For further explanations, see text. Reproduced and modified from [2] with permission.

TABLE 1 Common omics data types

	Assay	Platform	Main advantages and disadvantages	Standard bioinformatics pipelines
Genomics	Identify nucleotide variants (SNPs) in the whole genome associated with clinical traits (GWAS)	Genotyping arrays, whole-exome sequencing	SNP variability is stable during life; provides limited information in complex diseases due to several loci implicated	GWAS protocol review [10]
Transcriptomics	Quantify expression levels of cellular transcripts (e.g. mRNA)	Expression arrays, RNA sequencing	Widely used due to its high information content on cell status; differences in mRNA expression do not imply differences in proteins; does not take into account post-transcriptional modifications	RNA sequencing pipelines review [11]
Proteomics	Characterise protein expression levels of cells/samples	MS-based approaches	Expected to be closer to the phenotype; not widely used, expensive and more cumbersome analysis	Next-generation proteomics review [12]
Metabolomics	Characterise abundance profile of metabolites and their relative ratios	MS-based approaches	Representative of the cellular status; applicable to many biological fluids (i.e. breath, blood, urine, etc.); not widely used	Review of analytical methods for metabolomics [13]
Epigenomics	Determine modifications in DNA and small RNA that interfere with gene expression	DNA methylation analysis with arrays (Infinium MethylationEPIC 850K; Illumina, San Diego, CA, USA), next-generation sequencing, small RNA sequencing, arrays, etc.	Provides additional information to transcriptomics; related to exposures; more expensive than transcriptomics; sequencing-based approaches have computational tools in active development	Bioinformatics aspect of DNA methylation studies [14]
Microbiomics	Characterise bacterial (and viral) composition of a sample	Targeted sequencing of 16S rRNA gene, shotgun metagenomics sequencing	Provides information of external factors likely to be associated with disease; 16S sequencing does not differentiate between the presence of live/dead bacteria	Bioinformatics analysis for the characterisation of the human microbiome [15]

SNP: single nucleotide polymorphism; GWAS: genome-wide association study; MS: mass spectrometry.

PERSPECTIVE

entative, and
eep Apnea

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

2014



VIEWPOINT

Personomics

**Roy C. Ziegelstein,
MD, MACP**
Department of
Medicine, Johns
Hopkins University

*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

JAMA Internal Medicine

2015



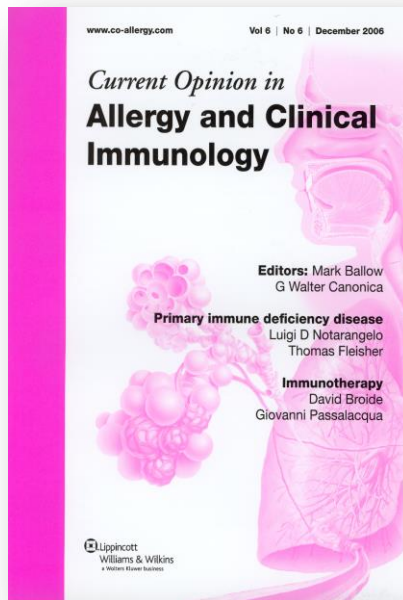
P4 Medicine: Personalized, Predictive, Preventive, Participatory

A Change of View that Changes Everything

Leroy E. Hood
Institute for Systems Biology

David J. Galas
Battelle Memorial Institute

Version 6: December 12, 2008¹



REVIEW

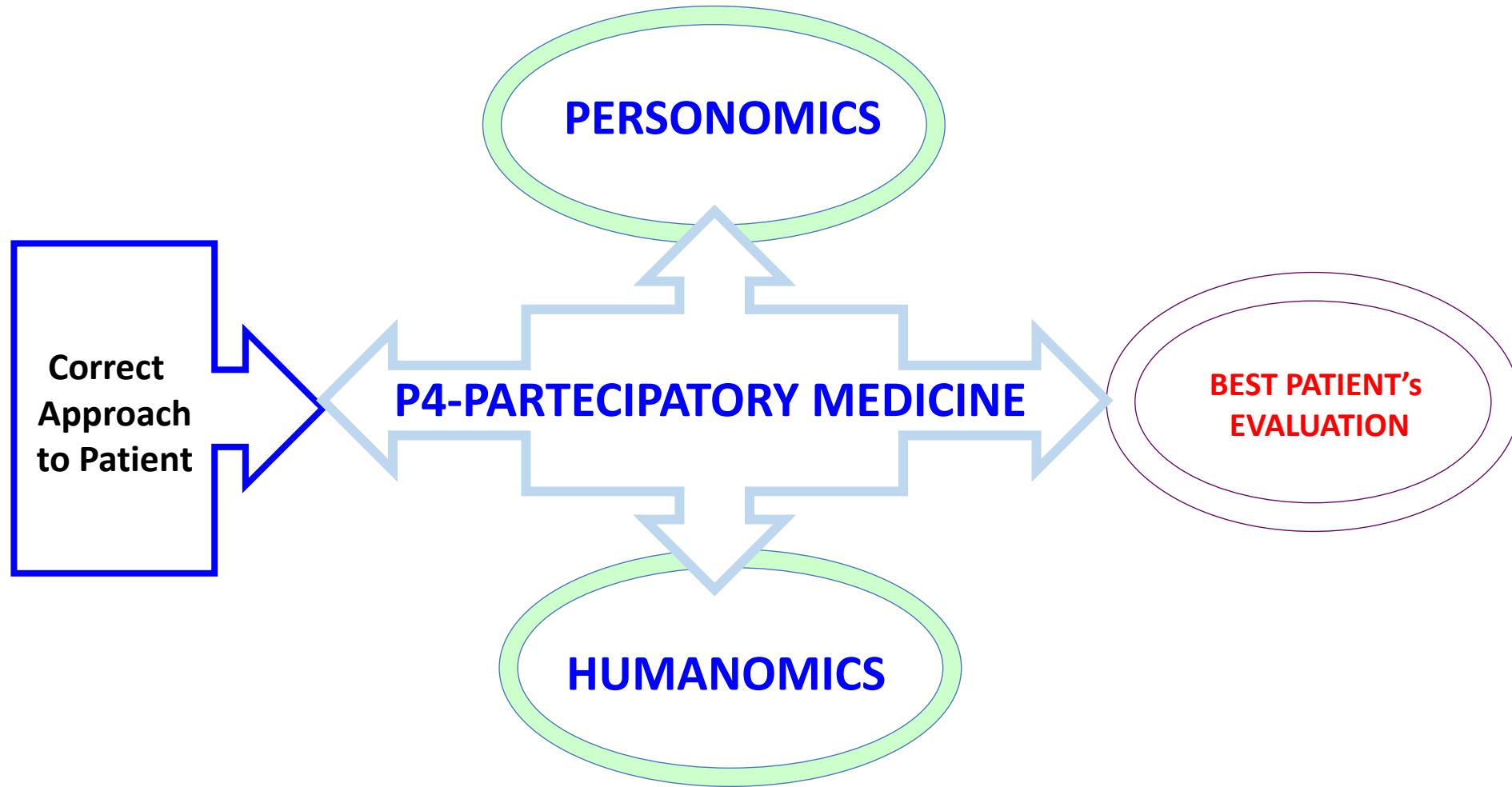


Asthma: personalized and precision medicine

*Giorgio W. Canonica^{a,b}, Matteo Ferrando^c, Ilaria Baiardini^c,
Francesca Puggioni^b, Francesca Racca^b, Giovanni Passalacqua^c,
and Enrico Heffler^{a,b}*

Canonica et al., COAI Dec 2017

STEPS FORWARD to BEST PATIENT's EVALUATION



Canonica et al., COAI Dec 2017

Fig.1

STEPS FORWARD to BEST TREATMENT

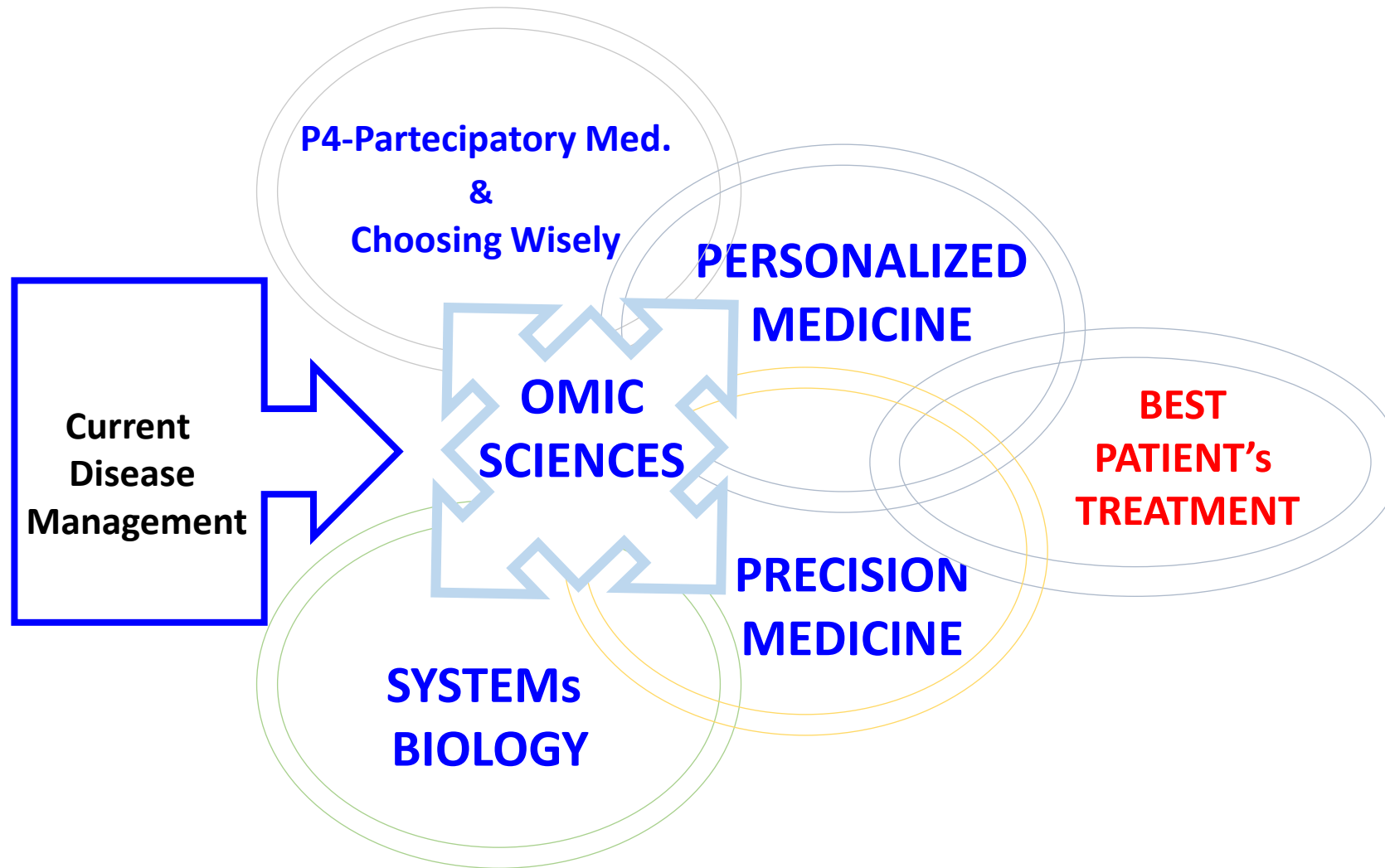


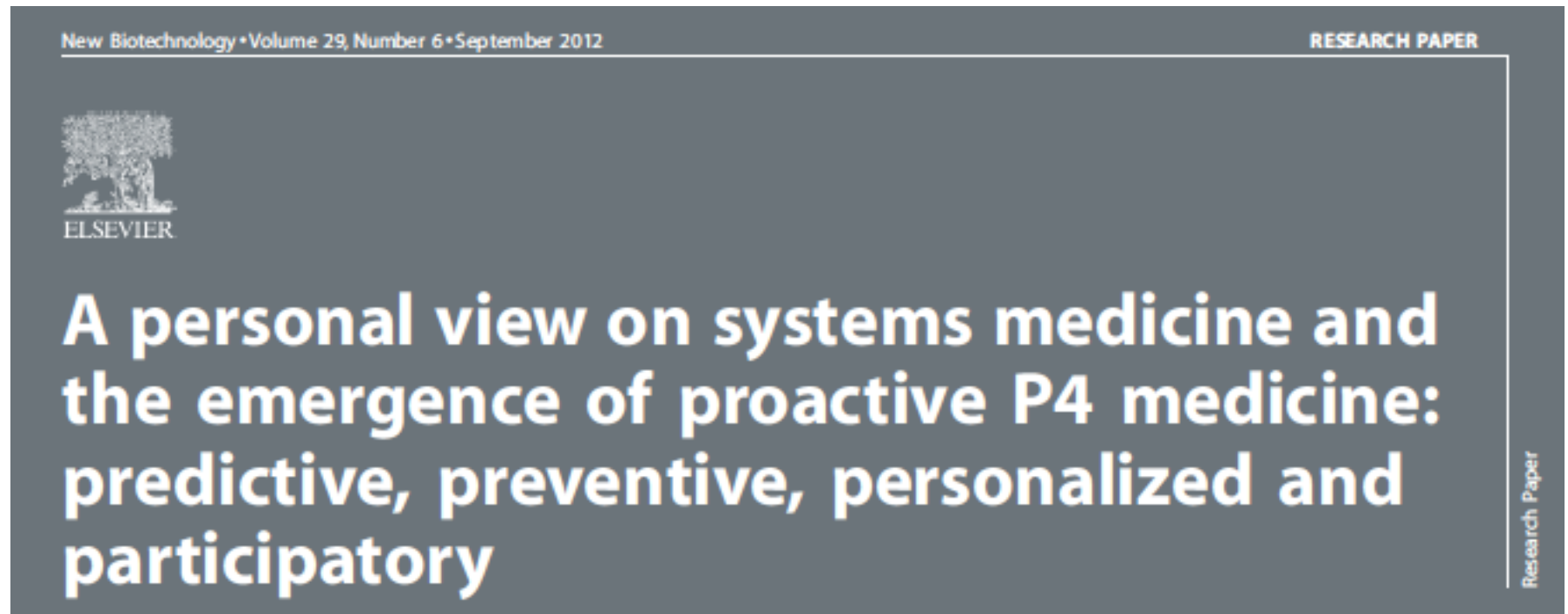
Fig.2

Canonica et al., COAI Dec 2017



Hood & Flores, New Biotechnology 2012

P4 Medicine
Predictive
Preventive
Personalized
Participatory



Leroy Hood¹ and Mauricio Flores²

¹ Institute for Systems Biology, 401N. Terry Ave, Seattle, WA 98121, USA

² P4 Medicine Institute, 401N. Terry Ave, Seattle, WA 98121, USA

Hood & Flores, New Biotechnology 2012

*Hood & Flores,
New Biotechnology 2012*



FIGURE 1

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

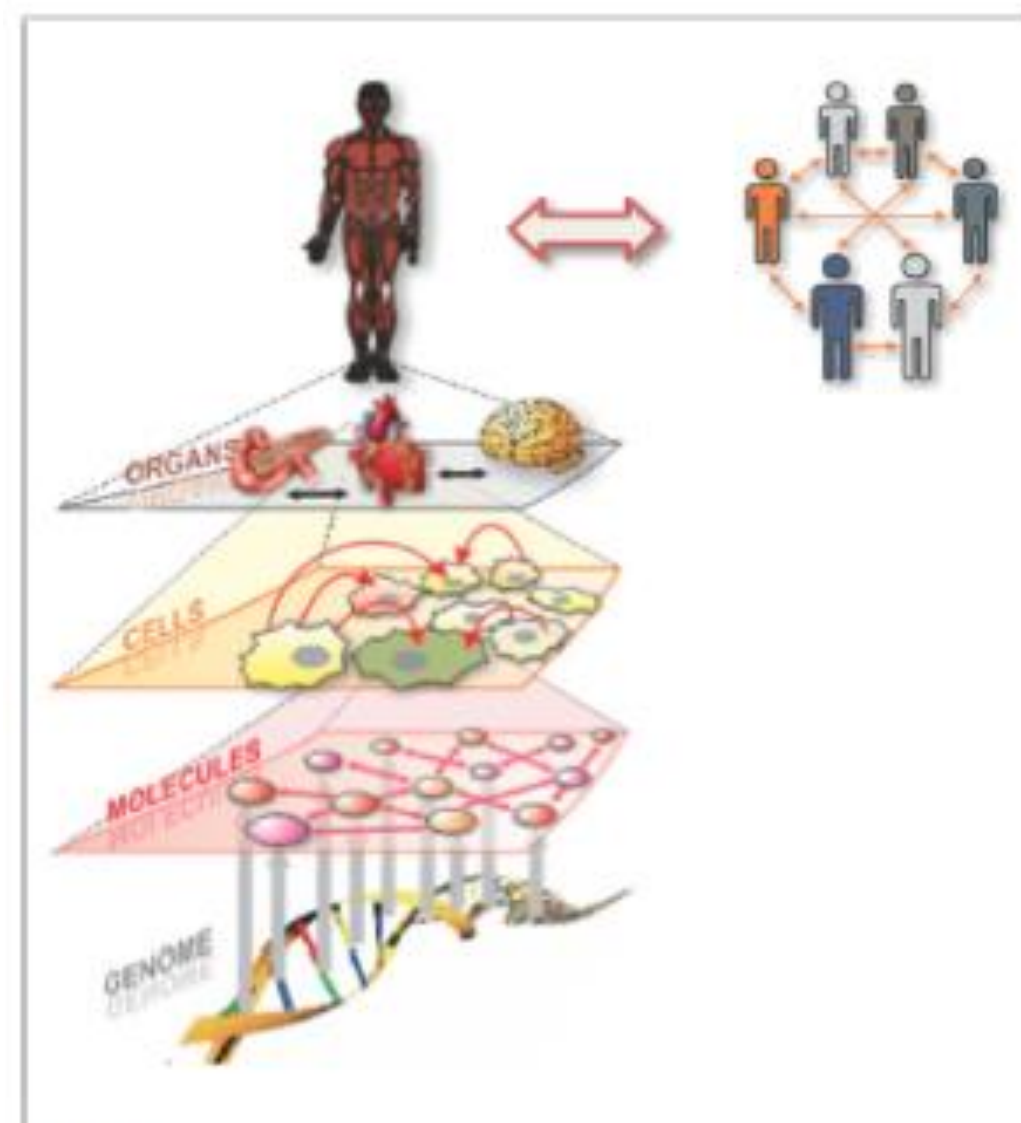


FIGURE 2

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

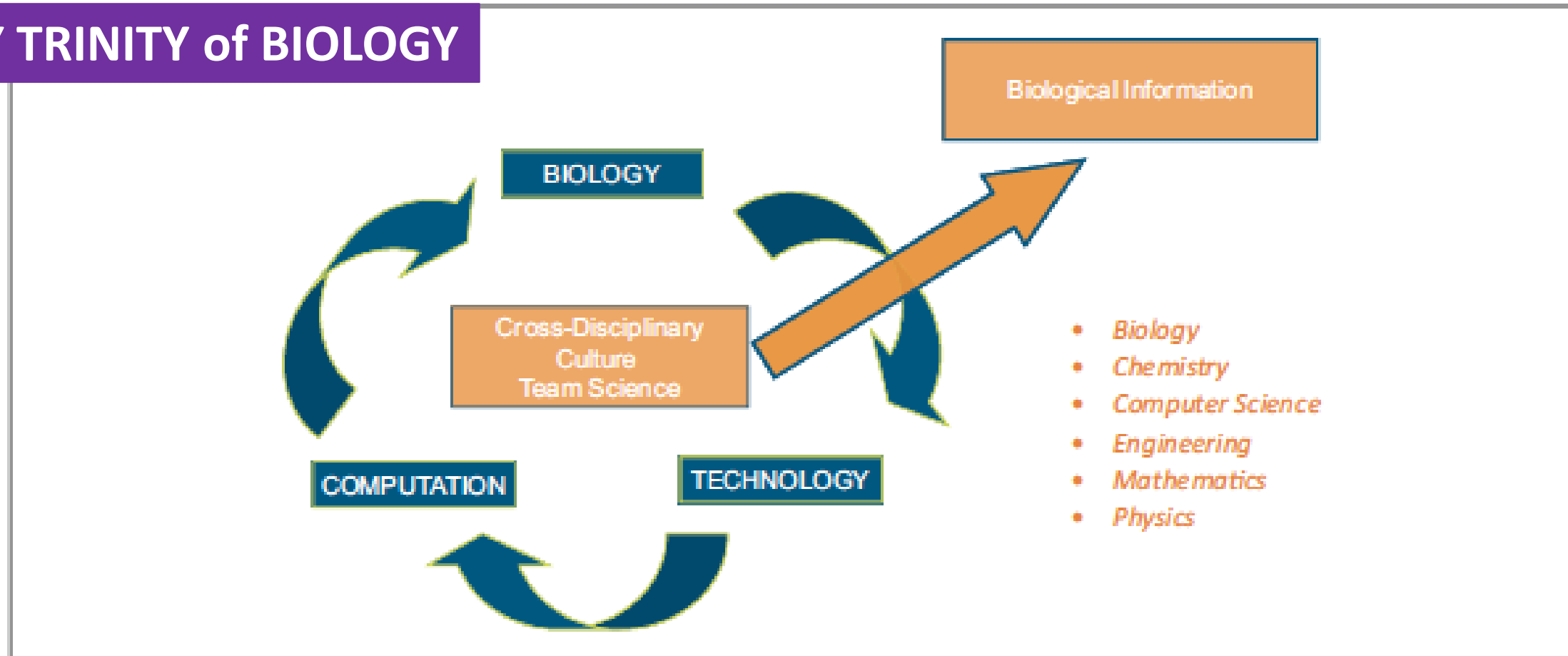


FIGURE 3

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.

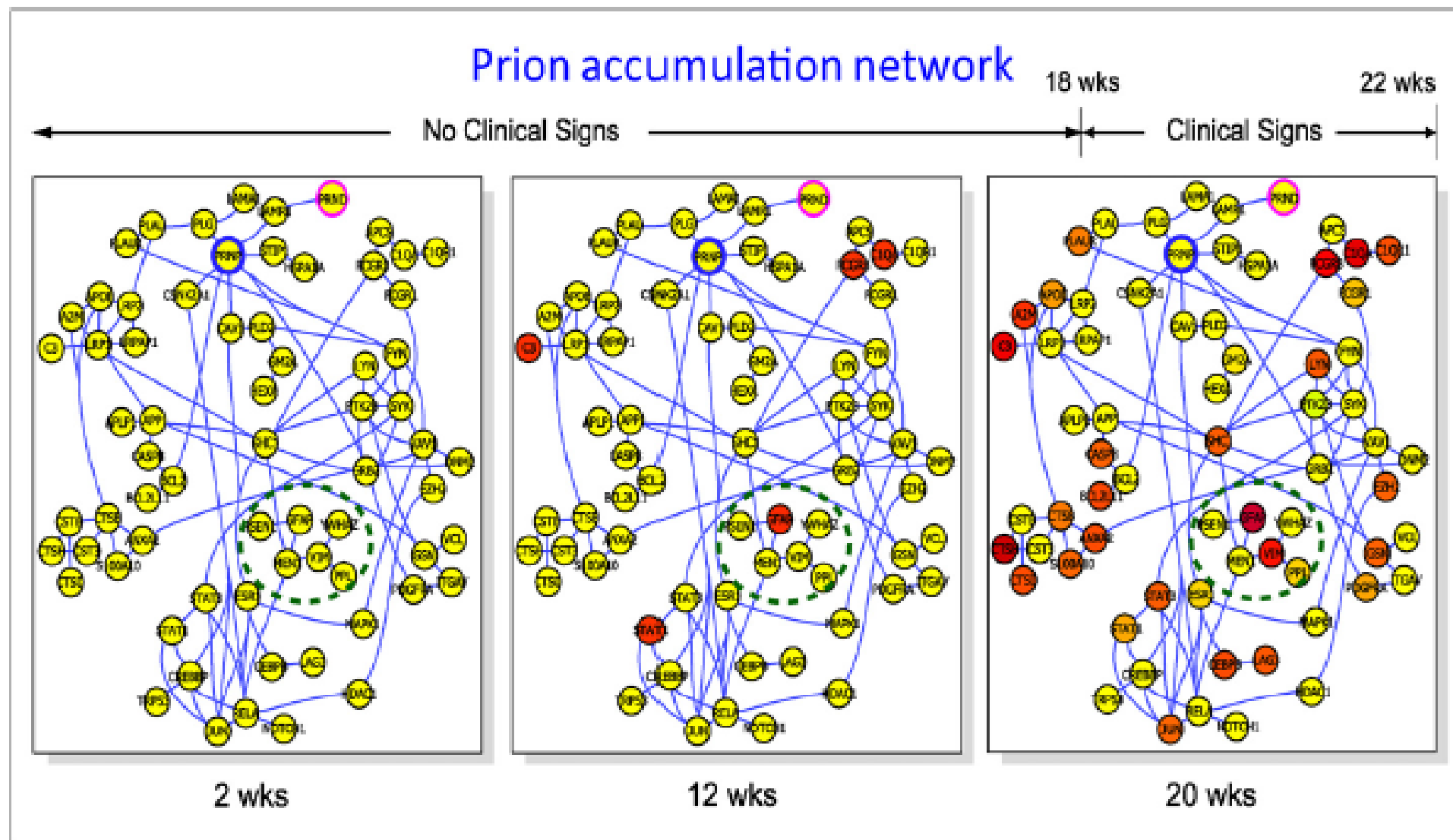


FIGURE 4

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.

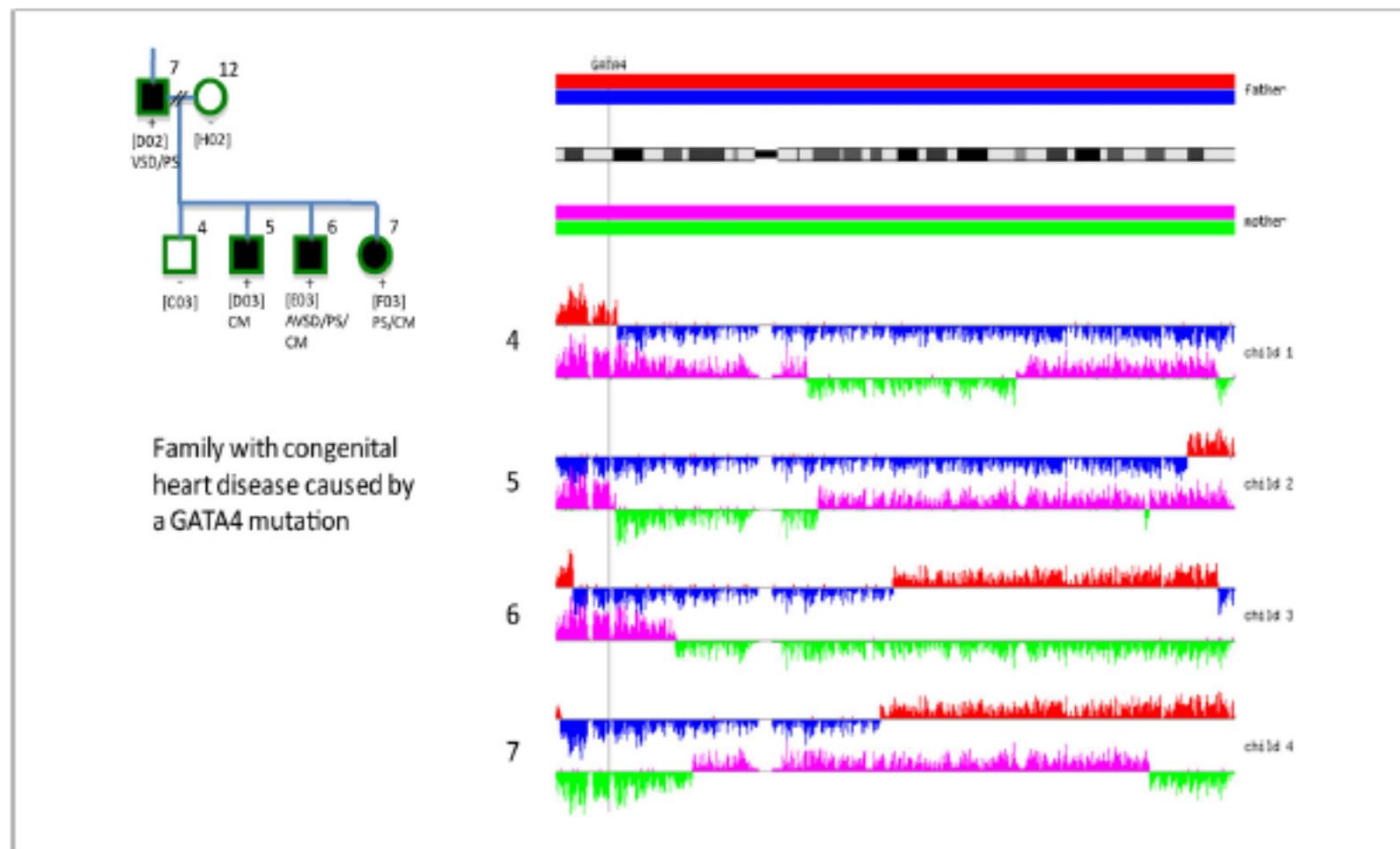


FIGURE 5

A schematic depicting the haplotypes of the members of a family of 6. The family tree is indicated at the left. The four parental haplotypes (two for each parent) are indicated by four different colors. The portions of the parental haplotypes that are passed on to each child are indicated by the same colors. Each color change denotes a site of chromosomal recombination. Family genome sequencing permits one to determine these recombinational sites with great precision. The important point is that the genes that cause particular diseases must reside in areas of shared haplotype by those individuals in the family exhibiting the disease.

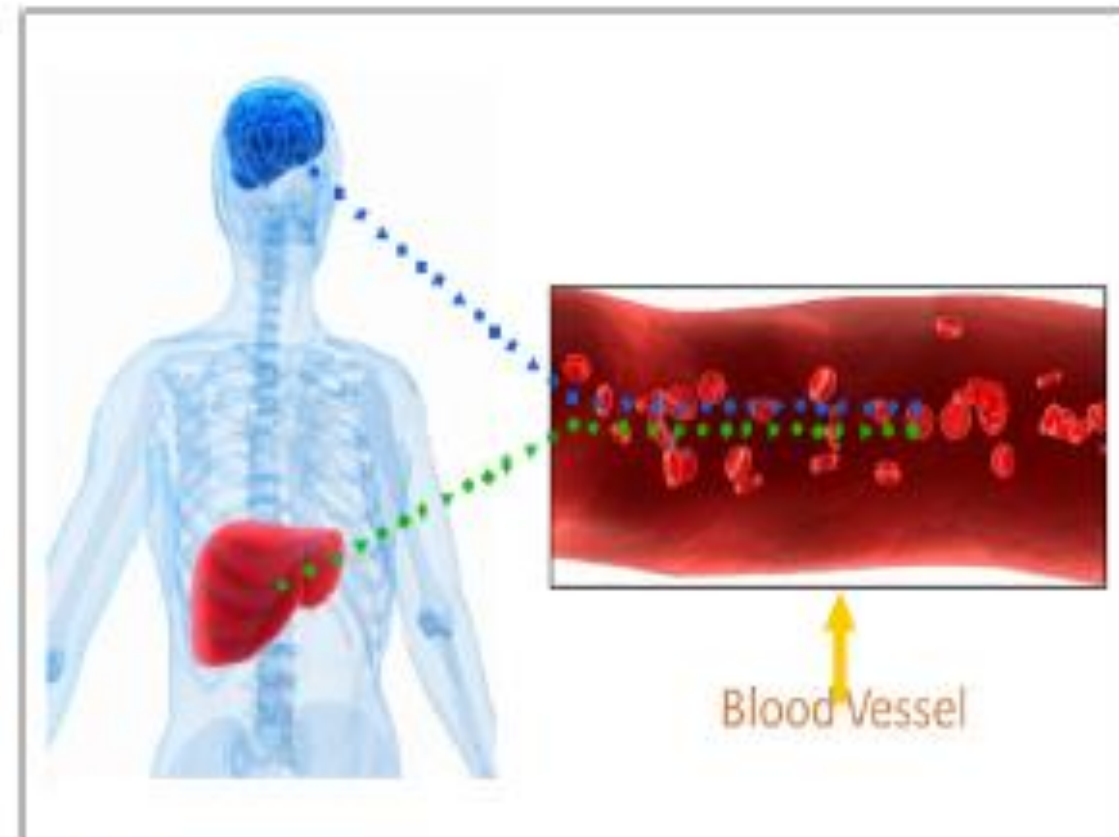


FIGURE 6

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).



Hood & Flores, New Biotechnology 2012

TABLE 1

A comparison of the current reactive, evidence-based medicine with proactive P4 medicine

Reactive medicine – evidence-based medicine

Reactive-respond after a patient is sick (symptom based)

Disease-treatment system

Few measurements

Disease-centric, with standard of care associated with population-based disease diagnosis

Records not highly linked

Large-scale diffusion of medical information mediated mostly through physicians alone

Drugs tested against large populations – 10s of thousands to develop statistics for FDA

Science based healthcare takes place almost entirely in clinics and hospitals

Discovery science and medicine are largely separate spheres of activity which communicate primarily through publication of articles in peer reviewed journals

Proactive P4 medicine

Proactive-responds before a patient is sick (based on pre-symptomatic markers)

Wellness-maintenance system

Many measurements, including complete genome sequencing, high-parameter blood diagnostics, many longitudinal omics measurements

Individual-centric, with standard of care tailored more fully to multiple measurements on the individual

Deeply integrated data that can be mined for continued improvement of healthcare strategies

Social networking of patients to enhanced shared experiences and diffusion of knowledge in consultation with their physicians

Stratification of disease populations into small groups, 50 or so, that can be effectively treated to achieve FDA approval

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

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



Hood & Flores, New Biotechnology 2012

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



Hood & Flores, New Biotechnology 2012

TABLE 2

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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



- *Hood & Flores, New Biotechnology 2012*

Systems biology

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



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.*

*Hood & Flores,
New Biotechnology 2012*

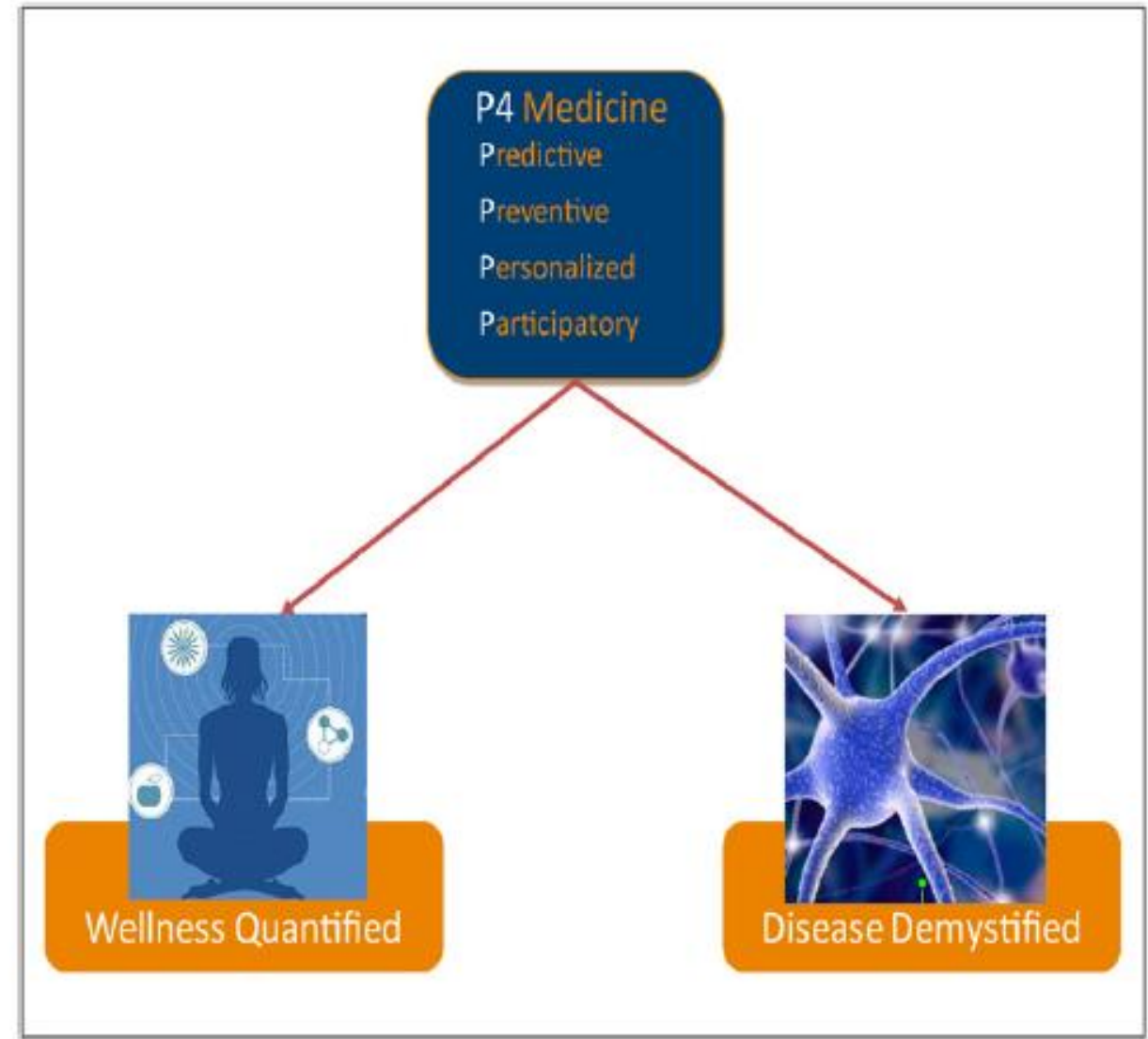


FIGURE 7

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

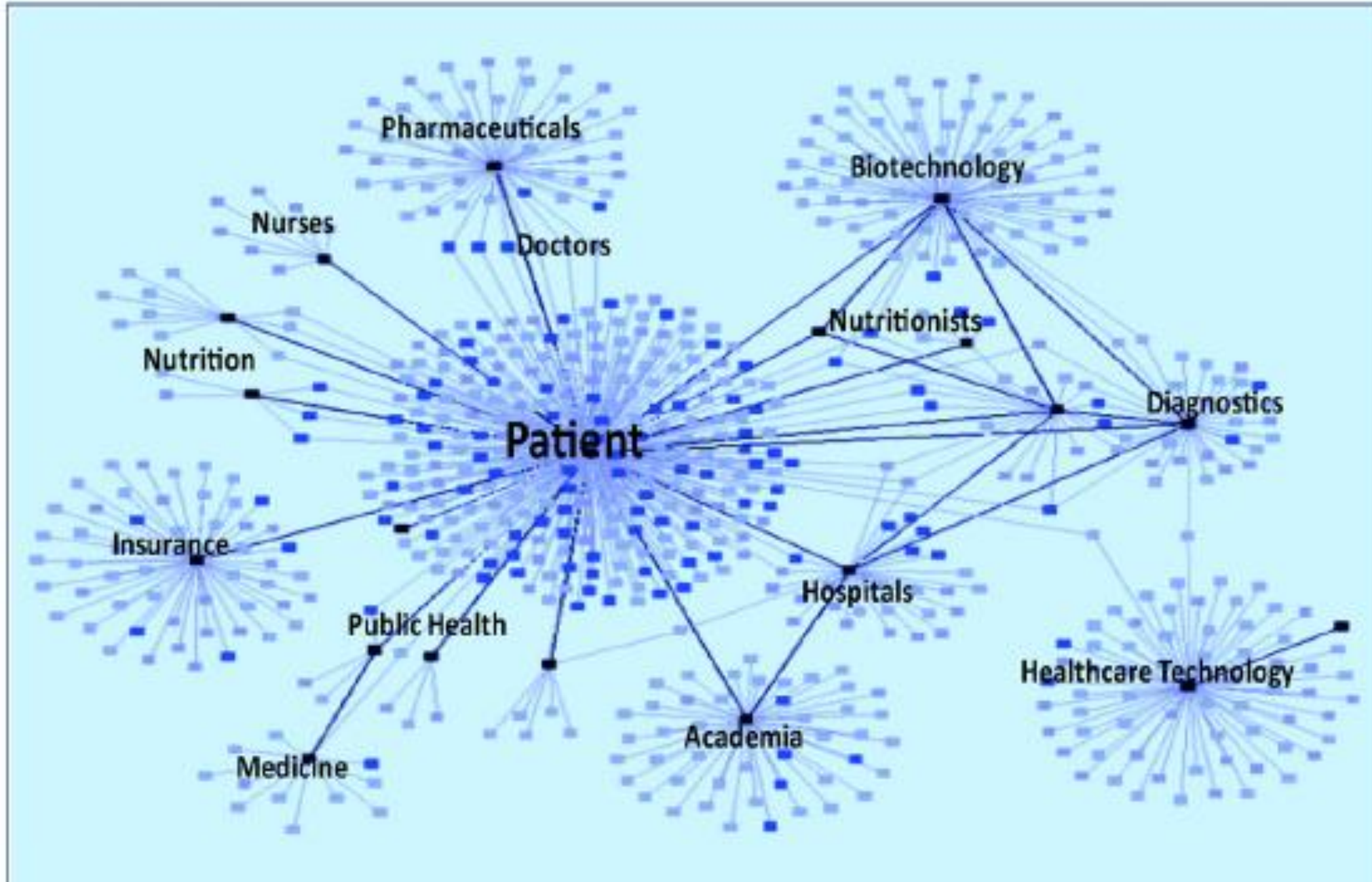


FIGURE 8

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.**



COMMENTARY

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 Fink-Wagner

PRINCIPLE 1: I DESERVE A TIMELY,
STRAIGHTFORWARD REFERRAL
WHEN MY SEVERE ASTHMA
CANNOT BE MANAGED
IN PRIMARY CARE

PRINCIPLE 2: I DESERVE A TIMELY,
FORMAL DIAGNOSIS OF MY SEVERE
ASTHMA BY AN EXPERT TEAM

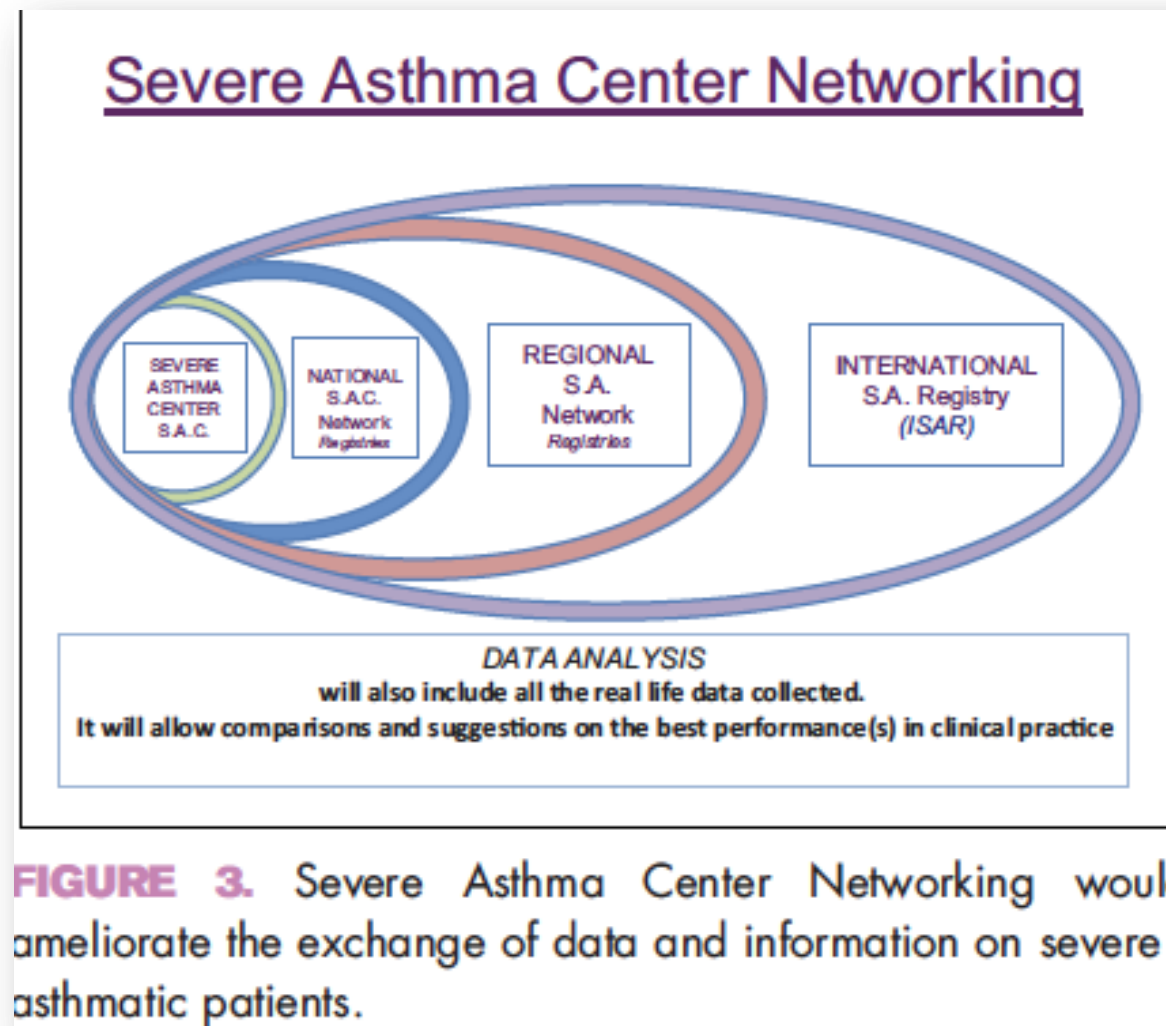
PRINCIPLE 3: I DESERVE SUPPORT
TO UNDERSTAND MY TYPE
OF SEVERE ASTHMA

PRINCIPLE 4: I DESERVE CARE
THAT REDUCES THE IMPACT
OF SEVERE ASTHMA ON MY DAILY
LIFE AND IMPROVES MY OVERALL
QUALITY OF CARE

PRINCIPLE 5: I DESERVE NOT TO BE
RELIANT ON ORAL
CORTICOSTEROIDS

PRINCIPLE 6: I DESERVE TO ACCESS
CONSISTENT QUALITY CARE,
REGARDLESS OF WHERE I LIVE
OR WHERE I CHOOSE TO ACCESS IT

- **New projects should be instrumental to provide answers to these points**



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](https://doi.org/10.2174/1381612820666140314145445)

VIEWPOINT

Personomics

Roy C. Ziegelstein,
MD, MACP
Department of
Medicine, Johns
Hopkins University

*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

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.

Ziegelstein JAMA Int.Med 2015

THANKS

PERSONALIZED MEDICINE ASTHMA & ALLERGY CLINIC



PUGGIONI Francesca
RACCA Francesca
MARSEGLIA Alessia
RONZONI Vanessa
LAMACCHIA Donatella
DiLUCA Fabrizio

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