

# **HIT Policy and Standards Committee Patient Generated Data Hearing**

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# Testimony

## **Panel 1: Uses of Patient Reported Information in Managing Health**

- Nikolai Kirienko, Patient
- Kate Goodrich/Patrick Conway, CMS
- David Lansky, Pacific Business Group on Health
- Philip Marshall, Healthline Networks

## **Panel 2: Emerging Practices**

- *Moderator: Leslie Kelly Hall*
- Judy Hibbard, University of Oregon
- Barbara Howard, CHADIS
- Elliot Fischer, Dartmouth
- Suzanne Heurtin-Roberts, National Cancer Institute
- Neil Wagle, Brigham and Women's Hospital
- John Amschler, Quantified Self

# Testimony

## **Panel 3: Policy Issues Related to Patient Reported Data**

- Deven McGraw, Health Privacy Project
- Prashila Dullabh, NORC
- Chad P. Brouillard, Foster & Eldridge, LLP

## **Panel 4: Challenges**

- Patti Brennan, Project Health Design
- Steve Downs, Robert Wood Johnson Foundation

## Overview

- CMS instruments HCAHPS and other patient reported outcome measures will grow
- Patient generated health data (PGHD) White paper presented
  - “PGHD complemented provider-directed capture and flow of health-related data across the health care system.”
  - Use cases and workflow technical descriptions
    - Foundation for S&I

## Overview

- PGHD are not equally helpful to every patient, provider, or situation in generating improvements in health
- Success shown where expectations set
  - Frequency of sharing
  - Data to share
  - Use by providers
  - Accuracy
- Patient reported outcomes can complement traditional clinical and administrative data

## Overview

- The physician is responsible only for the use of the PHR data that the physician has actively chosen..... and specifically incorporated into the patient's active medical care.
- Patient access to education materials important to avoid unnecessary communication
  - Literacy, language discussed
- PGHD is an important safety check

## Overview

- Consider Stage 2 MU support
  - Patient messages
  - Questionnaire responses
    - Previsit
    - Experience of care
    - Quality measures
- Consider Stage 3 MU support
  - Point of care
  - Patient initiated
  - Prior to visit
  - Collaborative care plans

## Overview

- Recommend a progression of measures
  - Volume of use
  - Types of use
  - Use itself
- White Board as a metaphor for collaborative care communication
  - Inpatient and beyond
- VA believes PGHD as a key component to improve care and health status

# Overview

- Emphasis
- Experience and value
  - Improving health status
  - Standardization
  - Sharing and Workflow
  - Synchronization
  - Security
- Registries as an important part of PGHD collection and dissemination
- Mobile will be a game changer

## Overview

- Standards and structure of PGHD important for adoption and integration into workflow
- Validated tools for patient reported outcomes needed
- Investigate new ways PGHD to interoperate  
S&I recommended
  - API
  - DIRECT
  - Consolidate CDA

# Overview

- Patient reported outcomes PROMS
  - Multimodal delivery and collection
    - IVR
    - Patient facing system
  - Concerns upfront
    - Workflow
    - Information overload
    - Liability
  - Implementation gone better than expected
    - Patients positive
    - Workflow not adversely impacted

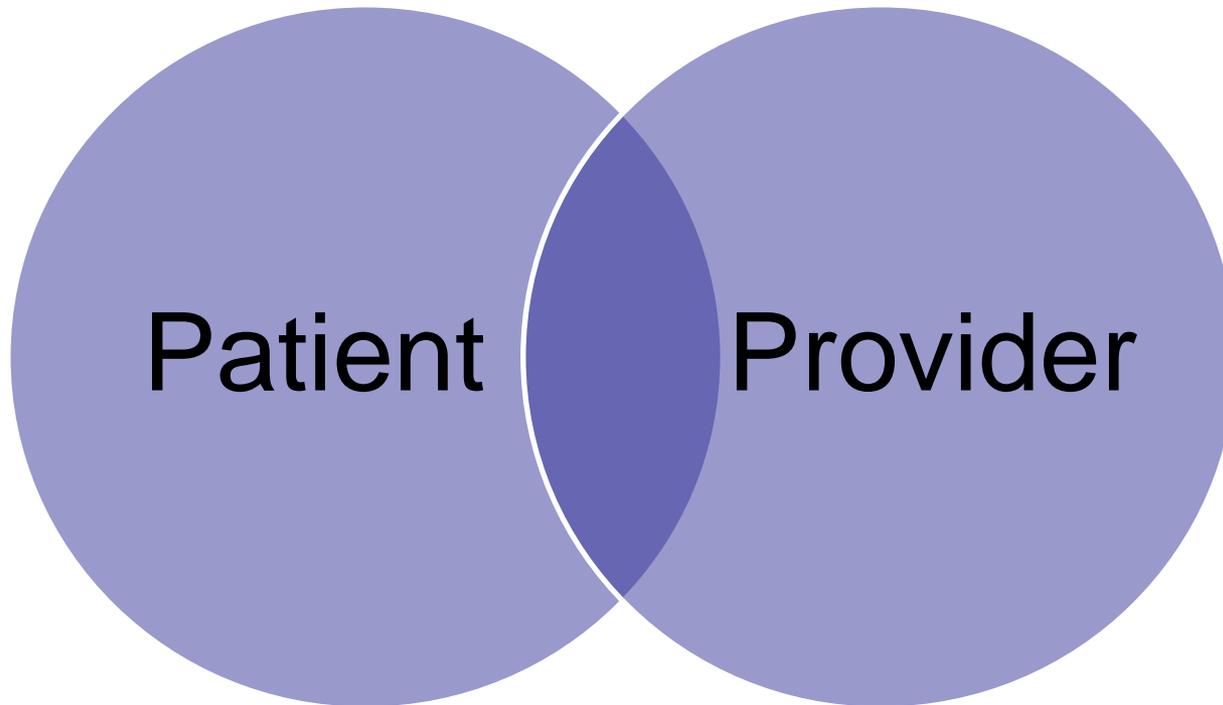
## Overview

- Patient Activation Measures (PAM) scores
  - PAM PGHD contribute to clinician understanding of patient knowledge, skill, and confidence for managing health
- Pediatric/family/physician PGHD high area of satisfaction and collaborative care
  - Modular approach for EHR “bolt ons” and PFS

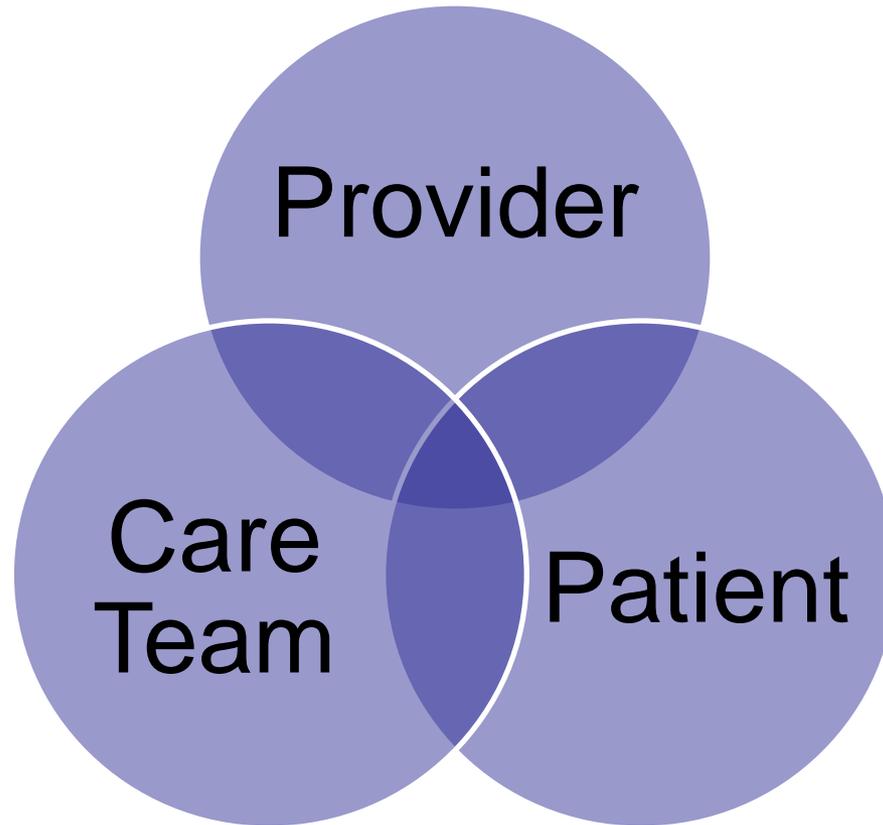
# Conclusions

- PGHD
  - Accepted into EHR
  - Standardized
  - Interoperable
  - Multiple respondents
  - Include patient facing systems
  - Shared decision making
  - Include expert systems outside EHR
  - Include Quality
  - Not limited by legacy systems

## Value of PGHD



# Value of PGHD



## Conclusions

- Standard of care is evolving and may include PGHD in the near future
- Where implemented PGHD has improved quality and patient confidence
- PGHD for values, intolerances, AD, and preferences may fit well within CPOE
- Workflow, structured data, and expectations should be well defined and understood
- New technologies like mobile health and new data sources may overwhelm providers who have not initiated structured PGHD efforts

## Conclusions

- Patients are the source of the majority of data in the record, PGHD is a logical next step
- PGHD matter because they allow clinicians to see a richer picture of the patient's day-to-day health
- All PGHD does not need to go into EHR
  - Incl necessary to clinical decision making
- Value based reimbursement may make PGHD more pervasive
- Concerns exist, however pilots proved positive

## Conclusions

- Patients are eager to participate and are more engaged in care and treatment
- Patients can provide accurate and useful information
- Processing PGHD will require computing and human intervention
- Attribution is an important part of acceptance
- Process for PGHD by providers will vary
- Data structure should standard and constant