


# ***"It's all about the Community"***

***Active community participation can differentiate  
Domain-specific open source projects***

# *Agenda*

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- Understanding market trends
  - Engaging domain experts
  - Managing existing domain content
  - Commercial and community contributions
  - Leveraging a successful community
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# ***Understanding Market Trends***

*“Obstacles are those frightful things you see when you take your eyes off your goal.”*

**Henry Ford**  
**Founder of the Ford Motor Company**




# ***Understanding Market Trends***

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- The healthcare and life sciences marketplace is rapidly transforming from several perspectives: business process, information, and technology
- Convergence and interoperability are critical to support improvements in care delivery and discovery
- Demands for affordable solutions
  - Affordability is one of main reason given for the lack of healthcare information and technology adoption in the US

# ***Understanding Market Trends***

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- If you don't understand the market, how can you solve the problem?
    - Open source communities must engage with an active customer community
  - Without a clear direction, it's very easy to develop a community that is *technology* rather than *solutions* driven
  - Creating an appropriate governance structure that includes domain expertise ensures a balanced approach
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# ***Engaging Domain Experts***

*“You do not really understand something unless you can explain it to your grandmother.”*

**Albert Einstein  
Nobel Prize Laureate (Physics)**



# ***Engaging Domain Experts***

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- The healthcare and life sciences market encompasses significant breadth
  - Informatics
  - Technology
  - Care Provision
  - Research
  - Personal Health
- No single organization, whether open source or proprietary, can effectively cover this breadth successfully

# *Engaging Domain Experts*

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- All open source projects need champions
  - Domain
    - Provides the market requirements
  - Technical
    - Mechanism to deliver
  - End Users
    - Validation that the solution meets the requirements

# *Engaging Domain Experts*

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- Attracting the best.....
  - Alignment of vision
  - Solving a common market requirement
  - Demand for execution

# ***Engaging Domain Experts***

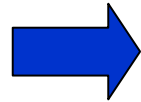
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- Example: A Customized Care Plan for Breast Cancer Patients\*
  - Development of a solution to help breast cancer patients better understand and proactively coordinate their care
- Working with domain experts
  - Physicians
  - Clinic Staff
  - Patients

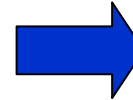
# Engaging Domain Experts



Isolation



Collaboration



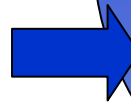
Empowerment

## Empower Clinicians and Patients

- Cancer treatment planning
- Support “bench-to-bedside” initiatives
- Collaboration



Best Practice



Replicable Solution



# ***Engaging Domain Experts***

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- Domain Experts
  - Effectively scoped the problem to be solved
  - Articulated the requirements for the solution that met the needs of all participants
  - Validated the solutions
- Technical Experts
  - Leveraged existing open source tools (e.g., Simile)

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# ***The Creation of Domain Content***

*“Better to keep your mouth shut and appear stupid than to open it and remove all doubt.”*

**Mark Twain**



# ***The Creation of Domain Content***

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- In the healthcare and life sciences marketplace we have no shortage of standards
  - Information Models
    - HL7 RIM, C-DASH, C-DISC etc.
  - Document Formats
    - CCR, CCD, CDA etc.
  - Terminologies
    - SNOMED, ICD 9, ICD10, CPT4 etc.
  - Messaging Structure
    - HL7 version X, C-DISC, DICOM, X12 etc.

# *The Creation of Domain Content*

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- “Interoperability” across healthcare and life sciences domains is essential to support the rapidly evolving healthcare and life science marketplace
  - Personalized Medicine
  - Adaptive Trials
  - “Bench-to-Bedside”
- The objective should be to embrace existing standards – not develop more!

# *The Creation of Domain Content*

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- Example: TRANSCEND
  - Demonstrate the integration of an electronic health record system with the bioinformatics infrastructure, and develop common data elements that are readily extensible to support multiple diseases
- Working with Existing Standards
  - Information Models
    - HL7 RIM, BRIDG and C-DASH
  - Terminology
    - CaDSR, SNOMED

# The Creation of Domain Content

The screenshot shows a WikiHIT page for the term "Temperature". The page has a navigation bar with tabs for "page", "discussion", "edit with form", "edit", "history", "move", and "watch". A "Report Issues" link is located in the top right corner. The main content area displays the following information:

- SNOMED**: [Body temperature finding \(SCT 105723007\)](#)
- Class (RIM)**: [Observation \(RIM\)](#)
- Alias**: TEMP
- Core**: Mandatory
- Datatype**: [PQ](#)
- Domain**: VS
- Length**: 12
- OID**: SCT 246508008
- Question**: What is the patient's temperature?

**Site Instructions** Collect this at time of vital signs collection

**Facts about Temperature** ⓘ

- Alias (CDASH)** TEMP + 🔍
- Class (RIM)** [Observation \(RIM\)](#) + 🔍
- Core (CDASH)** Mandatory + 🔍
- Datatype (CDASH)** [PQ](#) + 🔍
- Domain (CDASH)** VS + 🔍
- Length (CDASH)** 12 + 🔍
- OID (CDASH)** SCT 246508008 + 🔍
- Question (CDASH)** What is the patient's temperature?
- SNOMED** [Body temperature finding \(SCT 105723007\)](#) + 🔍
- Site Instructions (CDASH)** Collect this at time of vital signs collection

The left sidebar contains a "WikiHIT" logo, a "navigation" menu with links to Main Page, TC Home Page, Recent changes, and Help; a "search" box with "Go" and "Search" buttons; and a "toolbox" menu with links to What links here, Related changes, Special pages, Printable version, Permanent link, and Browse properties.


# ***The Creation of Domain Content***

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- Domain Experts
  - Effectively scoped the problem to be solved
  - Articulated the requirements for the solution that met the needs of all the participants
  - Validated the solutions
- Technical Experts
  - Leveraged existing standards
  - Developed open source tools to support the process

# ***The Creation of Domain Content***

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- Domain content should be freely available
    - Creative Commons
  - Projects can support vendor neutrality
    - Enable cross platform adoption
  - Governance process for control and updates
    - Ensure quality and adherence to standards
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# ***Commercial and Community Contributions***


*“We make a living by what we get, we make a life by what we give.”*

**Winston Churchill**



# ***Commercial and Community Contributions***

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- Developing a community of domain experts leads to innovation beyond that of technical contributions
  - Harnessing the breadth of the contributions often requires flexibility and a long term vision
  - Without direction, contributions can rapidly become under-utilized
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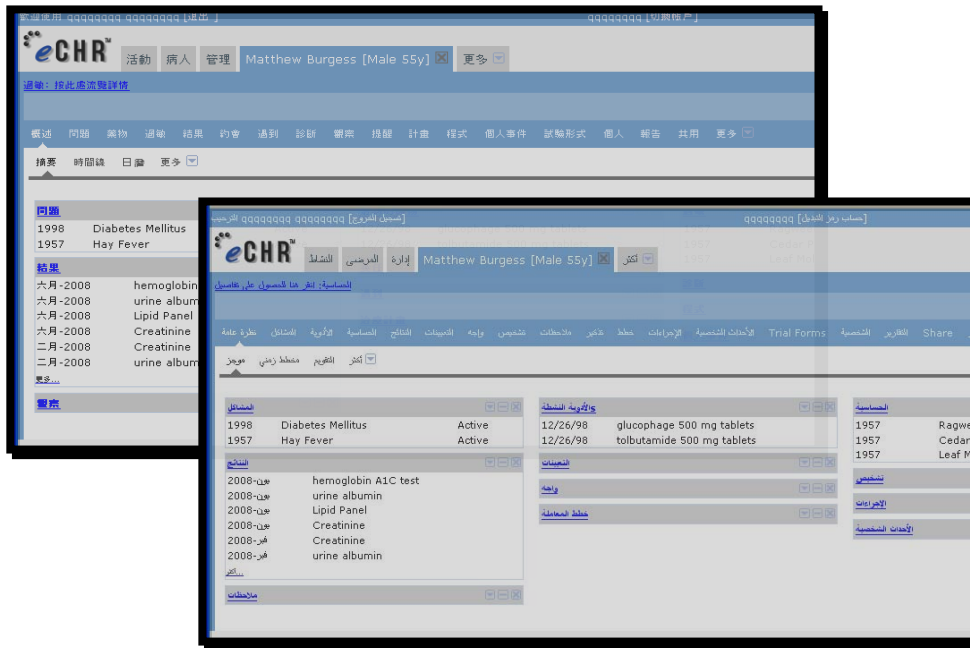
# ***Commercial and Community Contributions***

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- Example: Internationalization
  - There is a global demand for low cost, standards-based healthcare information technology solutions
  - To accelerate the availability of open source solutions across the globe, community members are willing to contribute knowledge
- Translations requires domain context
  - Domain experts contribute
    - Infertility specialist in Mumbai
    - HIV/AIDS clinic in Mozambique

# Commercial and Community Contributions

- Translation contributions
  - Spanish
  - French
  - Germany
  - Arabic
  - Chinese
  - Portuguese
  - Hindi
  - American English
  - Others




# ***Commercial and Community Contributions***

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- Domain Experts
  - Contextual translations
  - Quality assurance
  - Continued involvement in the update process
- Technical Experts
  - Resource bundle framework
  - Enhancements to make application translation process simple

# ***Commercial and Community Contributions***

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- Commercial organizations can be effective community contributors
  - Often driven by the opportunity to create market advantage
  - Contributions can be managed in such a way that they go back into the community
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# Commercial and Community Contributions

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- Example: Device Support
  - The cell phone marketplace is a multi-billion dollar industry that supports only a few healthcare and life sciences solutions
- Commercial Contributions
  - Research in Motion (RIM)
    - Devices
    - Access to technical support
    - Community promotion



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# ***Leveraging a Successful Community***

*“An ounce of loyalty is worth a pound of cleverness.”*

**Elbert Hubbard**



# *Leveraging a Successful Community*

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- A vibrant open source community requires balanced input from experts
  - Domain
  - Technology
  - Standards
  - Marketplace
- Leadership and Direction
  - At the helm of every community is a plan.....
  - At the heart of every community is knowledge....

# *Leveraging a Successful Community*

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- A successful open source community **MUST** be
  - Active
    - Executing on a mission
    - Welcoming and nurturing of new members
  - Reactive
    - Problem solving
    - Reactive to changes in the ecosystem
  - Proactive
    - Embrace domain and technical requirements
    - Embrace other projects

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# ***Summary***


*“A camel is a horse designed by a committee.”*

**Sir Alec Issigonis**



# *Summary*

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- Domain contributions are what turns a good technical architecture into an exceptional solution
  - Technical contributions are hugely important to any open source project
  - Clear leadership and direction are important to direct contributions
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# Summary

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- A properly orchestrated community avoids.....
  - Technically perfect – unusable solutions
  - Usable solutions – that have no market

*The code tells you what it's good for, but the community tells you what its future is!*



# ***Further Information***

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