ICADI Planning Workshop Notes Michael W. Vannier, MD

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These notes were written and organized in roughly chronological order to follow the discussion and presentations at the workshop. In many cases, they are my reaction to what was presented and not necessarily a transcript of the discussion itself.

Needs and Interventions Needs Assessment Who are the customers? What do they want? How can you tell if they receive the benefits? Where are the barriers? What is the product? How much does it cost, who will pay for it, and is it worthwhile? International interegovernmental interinstitutional collaborative Conference value - what is it intended to produce? idenfity opportunities report progress of ongoing work Dissemination websites special magazine issue Constituencies Aged and aging (frail, ill, healthy) ??? clinical trials (multicenter, randomized controlled trials) shared databases open source tools persistent infrastructure glue" grants private investment (and ROI) DFSS (1500 proposals to NSF ITR under review now) Any direct sharing of projects across UK-EU-USA?

Are needs changing? Goals not specific to individuals and don't include dates. What are the milestones and criteria for success?

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Entitlements - health care (with drug benefit) for over 65 Y.O. = Medicare, for example Mass customization

Objective driven research Exploratory research

Linkage with advocacy groups

Enabl er

www.cordis.lu/ist/so/einclusion

standards? intelligent devices / internet appliances the conventional internet is not sufficient

Necessary and sufficient

community intervention

Leveraged investments in technology Where is the ROI?

Faith-based initiative

Acceptance criteria healthy living: screening, compliance, follow-up (vs. single encounter)

Focus on economic viability; commercialization plans

Access to EQUAL Don't ask, "I want more QUality of Life" Is goal to change a rare event or

Personalize message, "Aunt Millie"

Information needs of Occupational Therapists CDC INPHO - Information Network for Public Health Organizations

Is it public health? Health and human services?

Proportionality: Are needs of aged and disabled more deserving of attention than other groups? \$/QALY\$

- Centers for rehabilitation research in US -- Preferable to independent RO1s Need for multidisciplinary approaches linked to users Critical mass of investigators
- Do Centers collaborate across institutional boundaries?

Life threatening conditions; end of life care social rules and moral acceptance

Where is the low hanging fruit?

Lunch at Dundee University for Nobel Prize winners, none of whom had ever applied for a research grant

No knowledge of variability - will any solution be sufficiently robust to be useful in actual setting

Hawthorne effect

Unbridgeable gap between need for medical and social care and the tax yield (VAT, income tax, NHI, etc.) How much of a "smart home" is necessarily useful for elderly? Innovation in the 21st century will take place not in science and technology, but in the organization of society using "contemporary" technology Use of surveys? Formal methods for customer needs assessment... Need for exercize?? Incentives?? Stop smoking. Need for community service. can it be subverted? is there a threat to privacy? patient with a fall and broken hip? stroke victim? heart attack? other life threatening event? Gloucester smart home "survey" == what is the N?? Sleep monitoring dementia Smart sensors with stove; smoke detectors, As an alternative to assisted living. User behaviour -- House reaction (example: night light) Caesar project - SAE - Engineering anthropometry Custom orthotics and prosthetics Prevention is much better than diagnosis and treatment monitor number of E.R. visits Pervasive computing lab - smart house - UFL - Gator-Tech Smart House Create a magic wand Mobile computing - elder digital assistant open framework development Ultrasonic location positioning / tracking system pilot and beacon Connect needs with source of disability - such as stroke, dementia (Alzheimer's Disease), ... Burden of disease; estimate of potential for gain; periodic monitoring of benefits (to give ROI) Specify targets (Healthy People 2000) Constituencies Frail elderly Medicare recipients Chronically ill Stoke victims Institutional i zed (demented patients, truants, young offenders, prisoners, soldiers in barracks, ...)

High risk (dementia, cancer, arthritis, heart disease/stroke, diabetes, depression) Hospi ce Rehabilitation / Recovery Substance abuse (behavioral intervention) Mental illness and neurological disorders (autism, substance abuse, obsessive-compulsive, schizophrenia, anorexia nervosa/bullemia, sleep disorders, phobias, sexual dysfunction, anxiety di sorders) Space travel - Space Station - Interplanetary travel Submari ners , ... Convergence of technologies: telephone, digital camera, cable television, Point of care systems Mobile healthcare: EMT, airport, police, firemen, nurses and clinics Assume that computers are free; sensors are omniscient, noiseless and ubiquitous; networks are 100% reliable and all data is immediately available everywhere. What needs to be done? Match the interventions to the need Gain acceptance Prove that the intervention makes a difference Show a benefit that is commensurate with the cost Is "home" enough? Disruptions are even more serious. Legacy facilities; retrofitting Nobody owns the whole process; most is out of control of government; what do the elderly want? what are they willing to accept? Visible Human Project Conceived in 3 phases: Collect the data
Organize and markup the images 3. Provide tools (software) to solve high level problems Digital Human concept Human performance labs (USAF) Engineering anthropometry Understand the natural history of chronic disease Instrument - Monitor - Evaluate - Intervene Reconcile interventions with life effects; Refine QOL measures Establish baseline perform intervention measure recovery reduce empiricism tailor interventions to individual needs

Interventions can be drugs, devices, procedures, ...

What's missing? no standards for data MIAME - Minimum information needed to define a microarray experiment Ontology for representation of information Information infrastructure Cyberinfrastructure

Personal security

How can you measure a baseline? Does it vary with genetics? How does it vary with age?

Characterize human performance. Human Factors.

What is normal aging?

Information Technology in Health Care (NIST)

Modeling human behaviors; modifying human behavior

What do customers want? What do they expect? What can be done for them that they don't ask for?

EMI and EMC in FDA device regulation?

HDTV station in Texas began and closed down a wireless cardiology clinic due to RFI.

Can you model nomadic wireless computer networks and predict failures?

Passive vs. active systems

User-centered design

Engineering meets behavioral science; nursing;

Variability???

Conceptual model of human environments -- model of human in the environment -- The Sims

Reality TV

Osbornes 12 strangers in same house Biosphere Frontier family in Kansas 1900's home in London

We are naturally curious about how humans behave in varying scenarios. For example, people watch reality TV to be Voyeurs and observe the actions of surrogates or counterparts.

The same is true in live theater, movies, TV sitcoms, dramas, mysteries, etc...