The California Electronic Death Registration System (CA-EDRS):

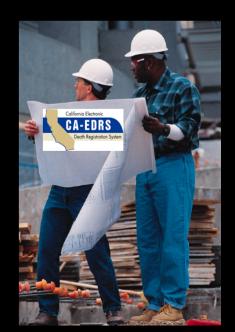
Building and Deploying a Mission Critical System for California

Michael Hogarth, MD Associate Professor, UC Davis School of Medicine Principal Investigator, CA-EDRS

Introduction

I am here to tell you a story... ...the story of how CA-EDRS was built

- By two California State organizations
- In 13 months
- From 'scratch'
- With a fixed budget
- With a fixed deadline
- Including special features never before built into similar systems



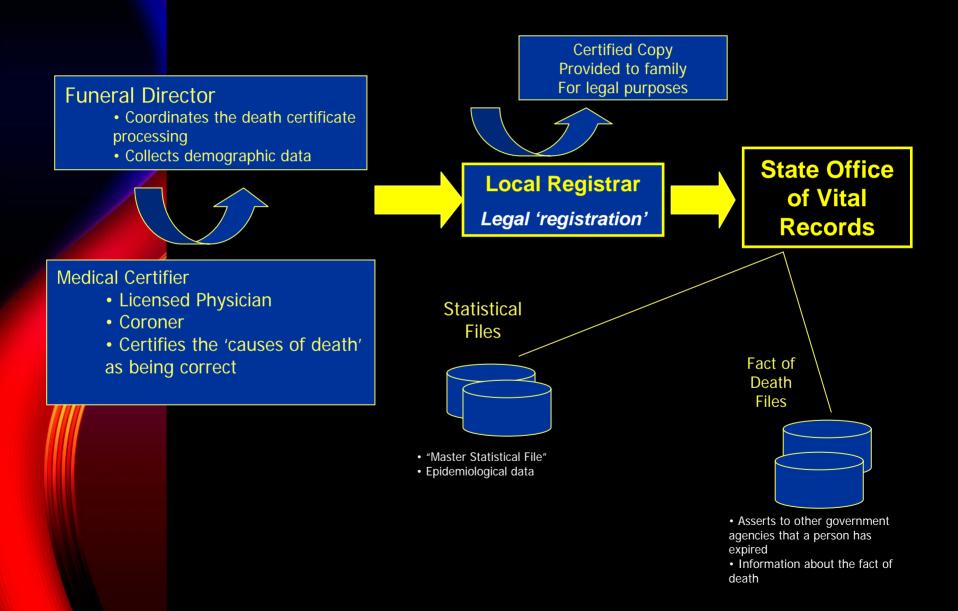
Death Certification in California

- 750 funeral homes
- 80,000 physicians
- 58 coroners/medical examiners
- 61 local registration districts
- Average 230,000 deaths annually
 - 1 out of 10 deaths in US occur in California
 - 1 out of 50 deaths (2%) in the US occur in Los Angeles county

How are death certificates used?

- A legal document stating the fact(s) of death
- A record of the disposition of the decedent
- Source of State and national mortality statistics
 - used to understand trends of disease and mortality
 - Used to to prioritize and allocate research funding

Death Certification -- a complex process



Who depends on death certificate data from California?

Federal agencies (5)

 National Center for Health Statistics (NCHS) · Social Security Administration (SSA) · Health and Human Services Agency · Federal Bureau of Investigation · Veterans Administration Medical Center

State agencies (24)

 Department of Social Services · Governor's Office · California Legislature · Legislative Analyst's Office · Attorney General's Office · Department of Finance · Department of Motor Vehicles · Secretary of State · Department of Consumer Affairs · Employment Development Department · State Teachers' Retirement System · Public Employees' Retirement System · State Public Defender · State Controller · Department of Justice · Department of Developmental Services · Franchise Tax Board · California Highway Patrol · Department of Industrial Relations · Consumer Product Safety Commission · · University of California (several campuses) · Office of Statewide Health Planning and Development · California Youth Authority · Department of Alcohol and Drug Programs

Current problems with death certification in California

Timely completion

 Only 11 of 61 (18%) local jurisdictions in California had 100% of their certificates registered within 14 days of death (the legal requirement)

Legal issues

~3-10% of California death certificates are signed illegally

Overpayment of benefits

- Estimated to cause <u>billions</u> per year in lost funding at the State and Federal levels
 - Finalized "fact of death" information is currently not available to governmental agencies for 6 - 10 months.

The cost of "fixing/correcting" death certificates

The State processes approximately 3,500 amendments per month, of which about 5-% are made necessary by erroneous data being present on the death certificate. Each amendment takes from eight to ten weeks to process.

Impact on public health and biomedical research

Statistical files take 8-12 months to generate for public use (just completed 2003)

CA-EDRS is born

- 2002 AB2550 is passed and mandates an EDR be built and running by Jan 1 2005. Funding from temporary increase in burial permit fee.
- 2003 A steering committee is formed with representatives from CFDA, Coroners Assoc, CMA, State and local registrars)
- July 2004 EDRS FSR submitted to Dept of Finance by DHS to gain authority to spend funds generated by AB 2550
- Nov 2004 DHS and UCDHS execute interagency agreement (IA) to build CA-EDRS

CA-EDRS in perspective

 By 2003, only four States had EDRS systems in use - none fully (NH, SD, MN, SC)

 New York City had a well-publicized failure -- \$5 million for an EDRS which was never completed

In addition...

---- CA-EDRS needed to have special features

CA-EDRS had to be a *hybrid* system

- paper-to-electronic ('batch entry')
- electronic-to-paper (drop to paper, dual pass)
- 100% electronic (electronic-to-electronic)
- Remote signature (attestation)
 - CA-EDRS had to let physicians sign remotely
 - Method chosen had to be
 - At no cost to participants
 - familiar enough to be intuitive and not require training of doctors
- Online SSN Verification (SSNV)
 - Only fully implemented by a few States-- all smaller than California
 - Requires rigorous testing process with SSA
- Extensive audit and security capabilities
 - Need to be able to detect fraudulent use of the system
 - SSL for all transactions, not just login

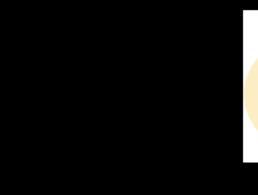
Drop to Paper Process



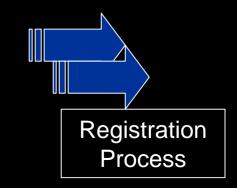




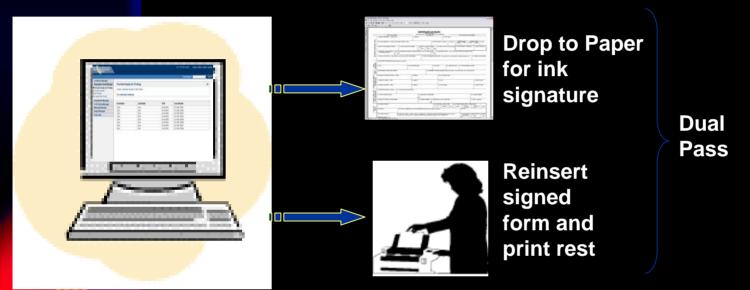








Dual-Pass Process







Remote "attestation" (signature)

California's challenges

- 81,000 licensed physicians
- ~30,000 are in specialties in which they might certify COD on a death certificate
- Over 90% do 1-2 certificates per year
 - unlikely to remember logins/passwords, how to use the system
- PIN-based signature is not legally acceptable for DCs in California.

A California advantage

 Law passed in 2003 - 'certification' of causes of death can be done using an "electronic signaturesubstitute approved by the State Registrar."

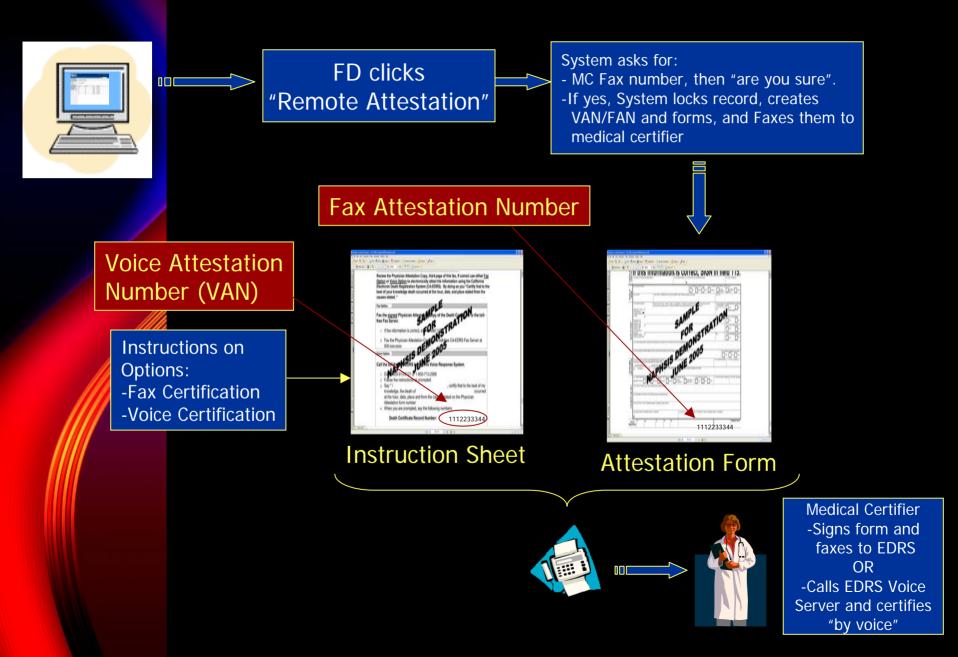
Our choices

- Electronic signature (pin based)
- "Signature dynamics" systems
- Digital certificates (PKI)
- Voice authentication systems
- Faxing signed documents (already allowed)

Our Approach to Remote Attestation

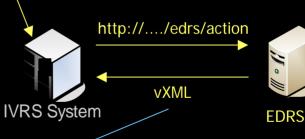
- Make it inexpensive for us and them
- Make it familiar
- Make it scalable
- Make it mobile
- Provide Non repudiation
 - must have a way that you can say with a high degree of certainty that 'that person signed this document'

The Remote Attestation Process



Voice system architecture

- **COTS Interactive Voice Response System** (VoiceGenie)
- VoiceXML input controls the voice server
- Button touches by user, cause IVRS to invoke URL on EDRS system
- EDRS generates VoiceXML files "on the fly" as reply to the IVRS
- IVRS system records the certifier statement and stores in an Oracle database in EDRS



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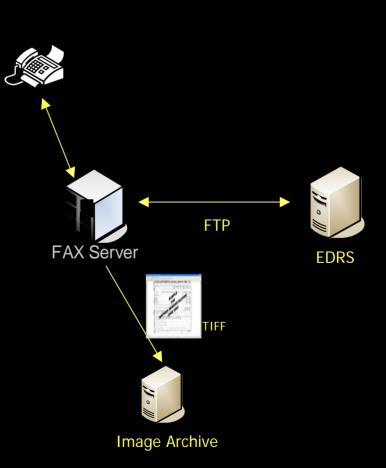
Example of voiceXML

<?xml version="1.0" encoding="UTF-8"?> <vxml version = "2.0" >

- <form>
- <block>
- <prompt>
- Hello World. This is my first telephone application.
- </prompt>
- </block>
- </form>
- </vxml>

Fax signature architecture

- COTS FAX server takes inbound fax (Acordex)
- Scans document into TIFF
- FAX server runs OCR subsystem
- OCR system identifies unique fax number and whether signature is present
- FAX server stores image in local repository
- Sends information to EDRS on inbound document and whether signature is present



SSNV

- Use an existing component from NAPHSIS that conducts the system-to-SSA communication/exchange
- Component built by Sybase, but they were no longer contracted with NAPHSIS, making changes to the component impossible
- Requires an extensive 16-week 'testing' cycle with the SSA

Auditing and security

Auditing

- Implemented a design that made each hyperlink 'clicked' an 'action' in the system
- All actions are logged in an activity history table which can be reviewed by the administrator

Security

- Actions have permissions
- User passwords encrypted with a one-way encryption method, then stored in the database
- All browser-server traffic is encrypted (SSL)
- Password expiration
- Login attempts 'time out'

And by the way... you really must be done on time

- California AB 2550 (2002) mandated an electronic death certification system be developed by DHS and deployed by January 2005.
- The State registrar had contracted with a third party to start keying all California 2005 certificates other than Riverside/Yolo into the system beginning in January

In summary

- We were asked to build a software system
 - That is highly reliable
 - That is highly scalable
 - Within a fixed short timeline
 - Within a fixed budget
 - For a process
 - That is complex
 - That is a over a century-old
 - Which involves stakeholders spanning five distinct groups/professions (mortuaries, coroners, physicians, health officers, local registrars)
 - Which does not tolerate a broken system
 - And... you must include several special features, some of which have never been implemented in an EDRS system (fax/voice attestation)

Death March projects

"A project in which an unbiased, objective risk assessment determines that the likelihood of failure is greater than 50%" ¹

"A project in which project parameters exceed the norm by at least 50%." $^{\rm 1}$

Usually means one or more of these constraints have been imposed on a project

- The schedule is half of what is estimated by a rational estimating process
- The staff is half of what would normally be assigned to a project of this size/scope
- The budget is half of what is normally expected
- The functionality, features, or performance requirements are twice what they would be under normal circumstances

Building software systems - risky business

- IBM's Consulting Group survey :
 - 55% of the software developed cost more that projected
 - 68% took longer to complete than predicted.
 - 88% had to be substantially redesigned.
- Standish Group Study of 8,380 software projects:
 - 31% of software projects were canceled before they were completed
 - 53% of those are completed cost an average of 189% of their original estimates.
 - 42% of completed projects have their original set of proposed features and functions.
 - 9% completed on time and on budget.

Dr. Kevin Engelhart, http://www.ee.unb.ca/kengleha/courses/CMPE3213/IntroToSoftwareEng.htm

Why do people participate in death march projects??

- Eternal optimism
- Your friend is running the project
- The "that's cool" factor
- Camaraderie
- Nothing better to do
- Blissful ignorance

Basic steps in software development

- Decide on your process to acquire the requirements such that they are easily and clearly understood
- 2. Decide how you are going to build the system
- 3. Decide how you are going to monitor the construction

CA-EDRS: Development Strategy

Use a reliable requirements gathering method

- Most projects that fail do so at the requirements gathering stage -- but nobody is aware of it until the end
- Use a highly iterative development process
- Deliver in stages (staged delivery)
- Monitor development closely

Requirements gathering

What is a "Use Case"?

- A formal way of describing how a system should perform, or allow the user to perform, and action
- Involves a narrative description and diagrams to describe interactions that need to be supported
- Diagrams are typically created using the Unified Modeling Language (UML)

CA-EDRS Use Cases

- Version 1.0 54 Use Cases
- Version 2.02 84 Use cases!
- Systems with over 30 use cases are considered 'complex'

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UCDHS BIRCS

The Regents of the University of California - IA # 03-75435 EDRS-D1005.2Bvs1 le. 0

34.CA-EDRS_UC_Local_Register

34.0 Revision History

Date	Version	Description	Author
01/21/04	0.1	CA-EDRS System process to register an electronic record at the Local Registration District.	G Gobar, L. Portigal, R. Palmieri
2/26/04	0.2	Review, edit, add diagrams	G Gobar, D Dumitru
5/30/04	0.3	Remove function to issue Disposition Permit to a separate use case.	G Gobar

34.1 Brief Description

This use case allows the LRD to review and register records submitted through the CA-EDRS. During this process a unique Local Registration Number (LRN) is automatically assigned and the electronic record is automatically forwarded to the State.

34.2 Actor(s)

- 34.2.1 Local Registrar
- 34.2.2 Local Deputy Registrar

34.3 Pre-Conditions

- 34.3.1 The Death Certificate Case exists in system.
- 34.3.2 The record has passed all edits.
- 34.3.3 The status of the Personal Information Section on the record is Authenticated.
- 34.3.4 The status of the Medical Information Section on the Record is Certified.
- 34.3.5 The record has been submitted to the Local Registrar, is electronic, and status is Submitted LR.
- 34.3.6 Logged on user is LR or Deputy LR with authority to register death certificates.

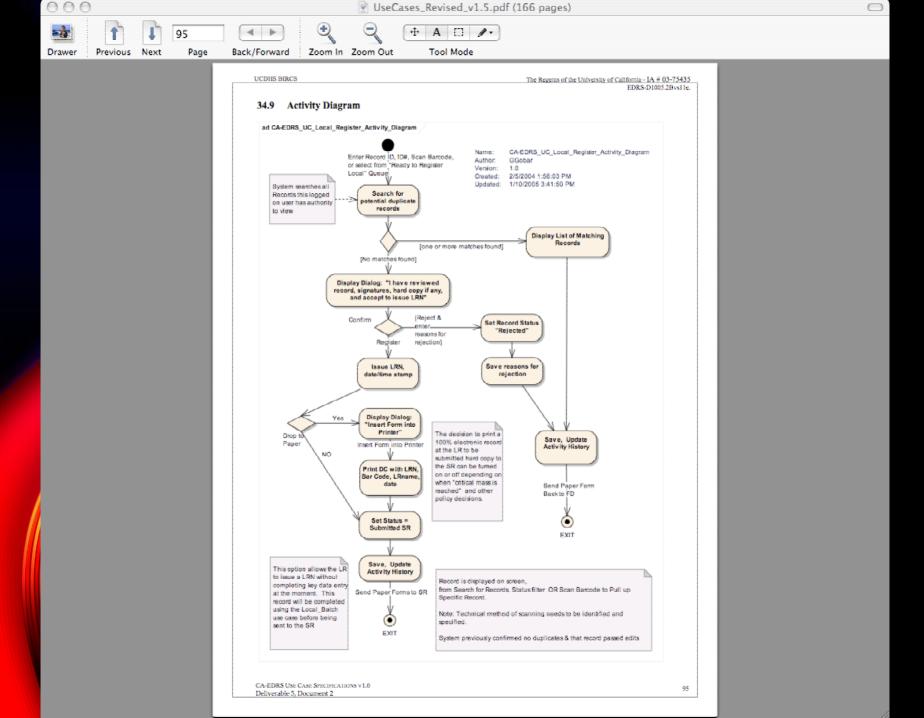
34.4 Flow of Events

34.4.1	Basic Flow

*****	10401011000	
1.		Display record Status is "Submitted LR"
2.	Review record.	Invoke CA-EDRS UC Duplicate Search
	Select option: Register Locally.	
3.		Display dialogue "I have reviewed record, signatures, hard copy if
		any, and accept to issue LRN"
4.		Display the selected record.
		Display options -
		Register Record
		Reject Record
		Text box: reason for rejection
5.	Select option	If selected Register Record, go to Basic Flow step 6
		If select Reject Record, go to Alternate Flow 4.2.1
6.		Populate jurisdictional entry fields: Local Registration Number,
		Local Registrar Name, User ID, and Date Registered.
7.		Update Record status to Submitted SR.
8.		Update Activity History.

CA-EDRS Use Case Specifications v1.0 Deliverable 5, Document 2

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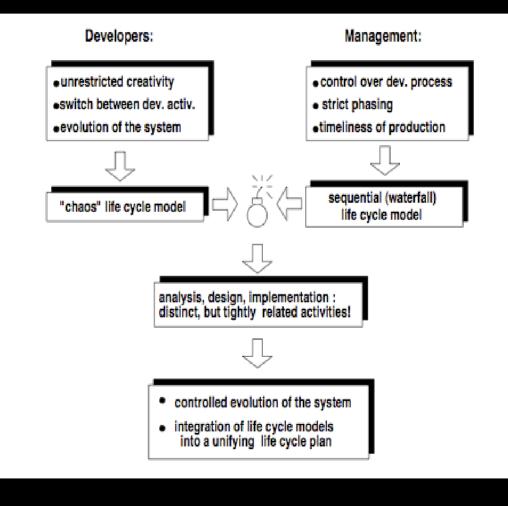
Software development models

Software development lifecycle (SDLC) models

- Waterfall
- Spiral
- Prototyping
- Evolutionary (Agile/XP)

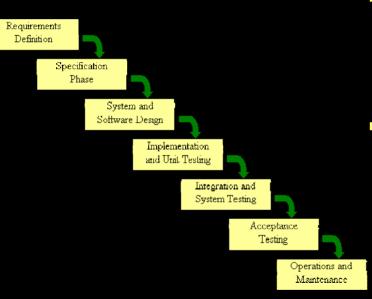


Reconciling different priorities in developing software



² Zamperoni et al. 1995

The Waterfall Model

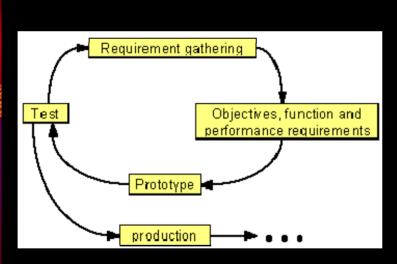


 The Waterfall Model continues to be used by many...

PROBLEMS -

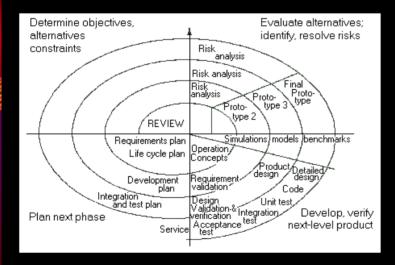
- The system is available for customer evaluation only at the end.
- Major errors in assumptions, workflow, processes are only uncovered late
- associated with high failure rates for projects and is not recommended

Rapid prototyping



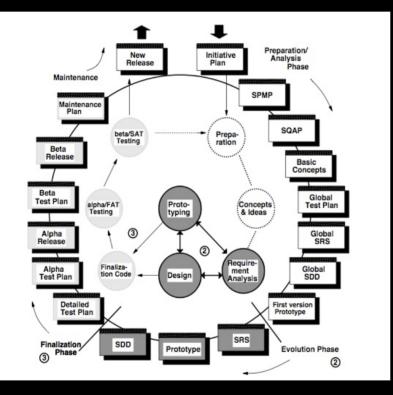
- A working prototype is provided to the customer/user early
- Allows for early assessment by the end user
- the prototype serves to clarify otherwise vague requirements
- PROBLEM -- the prototype is not 'the real thing'. The real thing requires building it so it is scalable and robust -not a prototype
- PROBLEM Engineers are tempted to 'add to the prototype' to build the real thing because of timelines

The Spiral Model



- A series of miniwaterfall cycles
- Prototypes are used in each step, with analysis then driving the building of the 'real thing'
- PROBLEM final product not available until the end

Evolutionary (Agile) Development



"Evolutionary"

- Software 'evolves' through rapid iterative cycles where the end-user interacts with the software from the start and provides feedback
- Many interim 'releases', each of which is a new version of 'the real thing' - but has more and more functionality
- PROBLEMS

- rapid changes can introduce bugs rapidly as well...
- requirements are only final with the release at the end of the project

Our four development principles

- #1: "Code" as little as possible
- #2: Deploy "early and frequently"
- #3: Code review must occur swiftly and in parallel with the development itself
- #4: The monitoring of the development process should not be intrusive

CA-EDRS and the four principles

- #1: "Code as little as possible"
 - Design patterns
 - leverage prior 'design templates' for specific types of components.
 - reflect common functionality so components are re-usable
 - Used existing (reliable) components
 - iText (PDF), Caspian (JSP/J2EE utility), Struts (MVC framework), Hibernate (object-to-relational mapping), barcode component
- #2: "Deploy early and frequently"
 - Used a highly iterative software lifecycle!
 - The CVS should always contain a 'buildable' and 'deployable' version of the software at the end of every day
 - "building" is the act of compiling the software
 - "deploying" is the act of making the system run on your architecture

CA-EDRS and the four principles

#3: "Code review while you build"

- Pair Programming
 - More than one has knowledge of the components
 - Code review occurred 'on the fly'

#4: "Monitor without intruding"

- Monitoring was a side effect of the requirements and testing process
 - Use Cases --> Features --> Tests
 - Feature and test completion --> rate of completion

Monitoring construction...

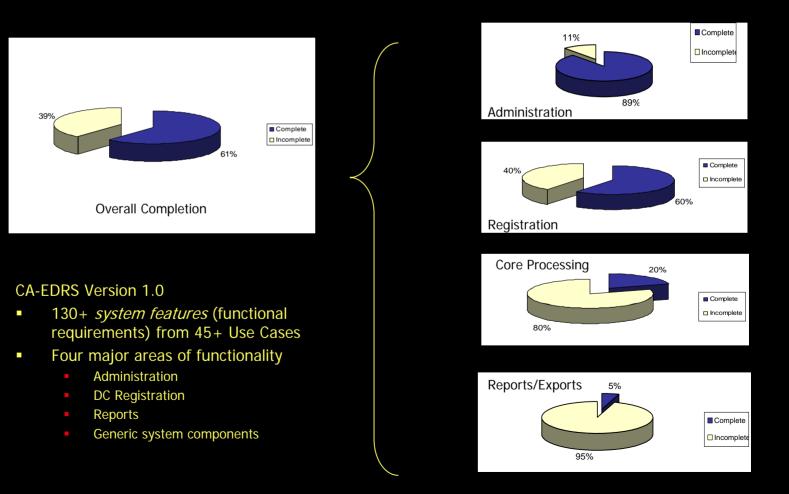
- Monitoring of 'programming completion' is difficult
- Our approach -- break up the system into functional parts, which are then itemized in a feature list and tracked
- Itemize by 'feature' and 'test'
 - Features were derived from the 'use cases', which described the required functionality in detail
 - The completion of features was monitored on a weekly basis

CA-EDRS v1.1 Feature List

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5					authorized users											[
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	F104	System	Permissions	Electronic	Allow the SR or a deputy SR to void a registered	1.1	10/11/04	100									VOID RE										
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Tracking CA-EDRS Construction

Start: 7/1/2004 Today: 9/14/2004 (@75 days/~10 weeks)



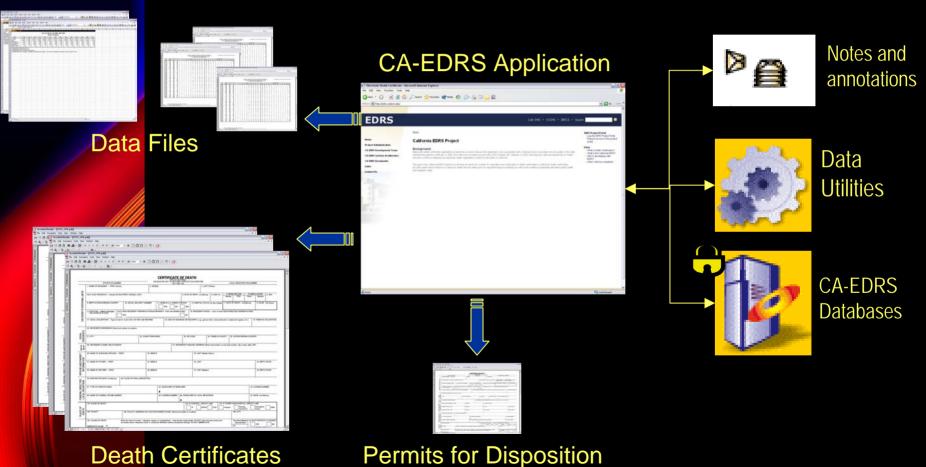
Death March Negotiating: Staged Delivery

- Staged Delivery
 - V1.0 Dec 2004
 - Core system user account management, death certificates, disposition permits, coroner referral, LR review/registration, SR registration
 - V1.1 Feb 2005
 - coroner amendments, batch death certificate entry, barcode reading and generation
 - V1.5 Apr 2005
 - general amendments, spell checking, context sensitive help, reports
 - V2.0 Jun 2005
 - remote attestation, aggregated data export
 - V2.1 Dec 2005
 - SSN verification, case-based export, MySearch feature

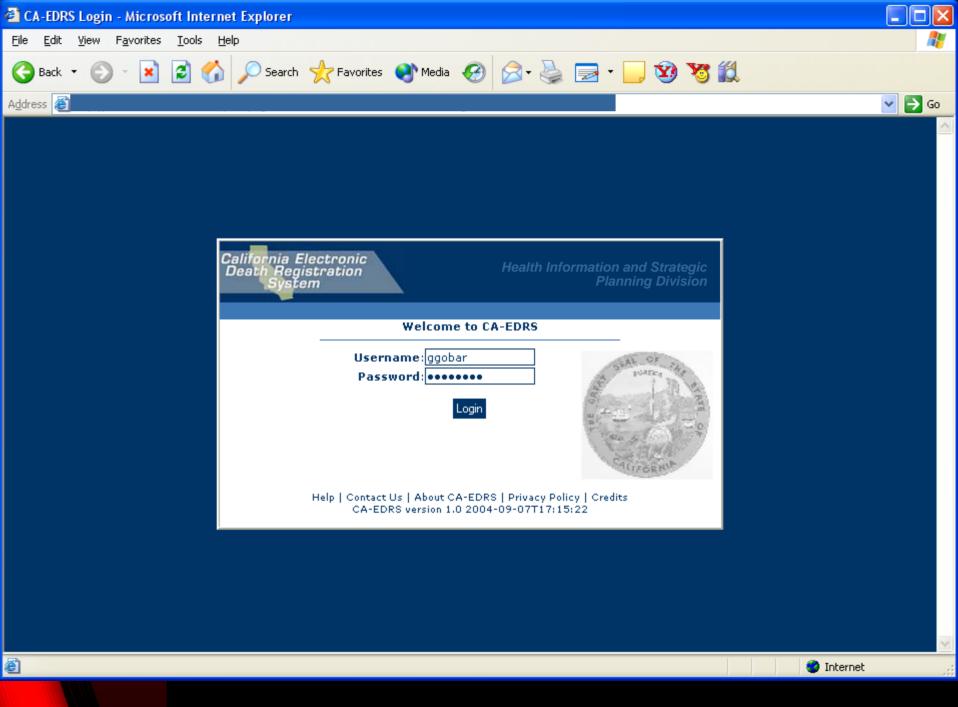
CA-EDRS development summary

- Jul 2003 CA-EDRS Steering Committee representing major stakeholders finalizes requirements
- Nov 2003 DHS and UCDHS finalize a contract to build CA-EDRS
- Feb 2004 First programmer's first day on the job
- Jul 2004 First 'line of code' written
- Aug 2004 First 'evolutionary' version of EDRS log in and user management components
- Nov 2004 Formal testing of EDRS v1.0 begins
- Dec 2004 Training of Yolo and Riverside county users
- Dec 27, 2004 CA-EDRS v1.0 deployed to production server
- Feb 2005 CA-EDRS v1.1....Dec 2005 CA-EDRS v2.1

CA-EDRS Application Overview



CA-EDRS - Let's see it!



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Amendment	Decedent Information	Record Access Control	
Disposition Permit	First Name: Mickey Last Name: Mouse Date of Death: 9/3/2004	Where applicable, indicate below who will have access to this record. If the Funeral Home is known, please select it: Funeral Home: GG Demo Funeral Home If the Hospital or Medical Facility is known, please select it: Medical Facility: Sutter Hospital If the place of death is known, please select the appropriate Local Registration District: Local Registration District: District:	
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1. NAME OF DECEDENT FIRST (Given) 2. MIDDLE 3. LAST (Family)	
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9. BIRTH STATE/FOREIGN COUNTRY California	8. HOUR (24 Hours) 1100
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13. EDUCATION Highest Level/Degree VES Never Married Annulled Unknown	×
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conditions, if any, leading to cause on Line A. Enter UNDERLYING CAUSE (B)	GROVE STREET HOME HARBOR VILLA CARE CENTER HARRIET HOME HEATHER LANE HOME KAISER FOUNDATION HOSPITAL, ANAHEIM	509 S GROVE STREET 861 S HARBOR BLVD 9802 HARRIET LANE 1748 HEATHER LANE 441 LAKEVIEW AVENUE	ANAHEIM 928 ANAHEIM 928 ANAHEIM 928 ANAHEIM 928 ANAHEIM 928 ANAHEIM 928	05 Address: 04 City: Anaheim 02 zip:					
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initiated the events resulting in death)	LEISURE COURT NURSING CENTER LIBERTY HOUSE MAGNOLIA RESIDENTIAL HOME	1135 LEISURE COURT 1133 LIBERTY LANE 804 N MAGNOLIA STREET	ANAHEIM 928 ANAHEIM 928 ANAHEIM 928	05					
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113. WAS OPERATION PERFORMED FOR ANY		1514 E LINCOLN AVENUE	ANAHEIM 928						
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104. COUNTY 105. FACILITY ADDRESS OR LOCATION WHERE FOUND (Street and number or location) 106. CITY 441 LAKEVIEW AVENUE ANAHEIM	
107. CAUSE OF DEATH Time Interval 108. DEATH REPORTED TO IMMEDIATE CAUSE NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation Onset and (Final disease or condition resulting in death) VES ONO NO Sequentially, list conditions, if any, leading to cause on Leading to cause on Image: Cause on	
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(C) (CT) 110. AUTOPSY PERFORMED?	
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112. OTHER SIGNIFICANT CONDITIONS CONTRIBUTING TO DEATH BUT NOT RESULTING IN THE UNDERLYING CAUSE GIVEN IN 107	
113. WAS OPERATION PERFORMED FOR ANY CONDITION IN ITEM 107 or 112? (If yes, list type of operation and 113A. IF FEMALE, PREGNANT IN LAST YEAR?	~
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31. NAME OF FATHER FIRST	20. DECEDENT'S REGIDENCE (Street and number or location)	
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35. NAME OF MOTHER FIRST test	21. CITY 22. COUNTY/PROVINCE 23. ZIP CODE 24. YEARS IN COUNTY 25. STATE/FOREIGN COUNTRY	
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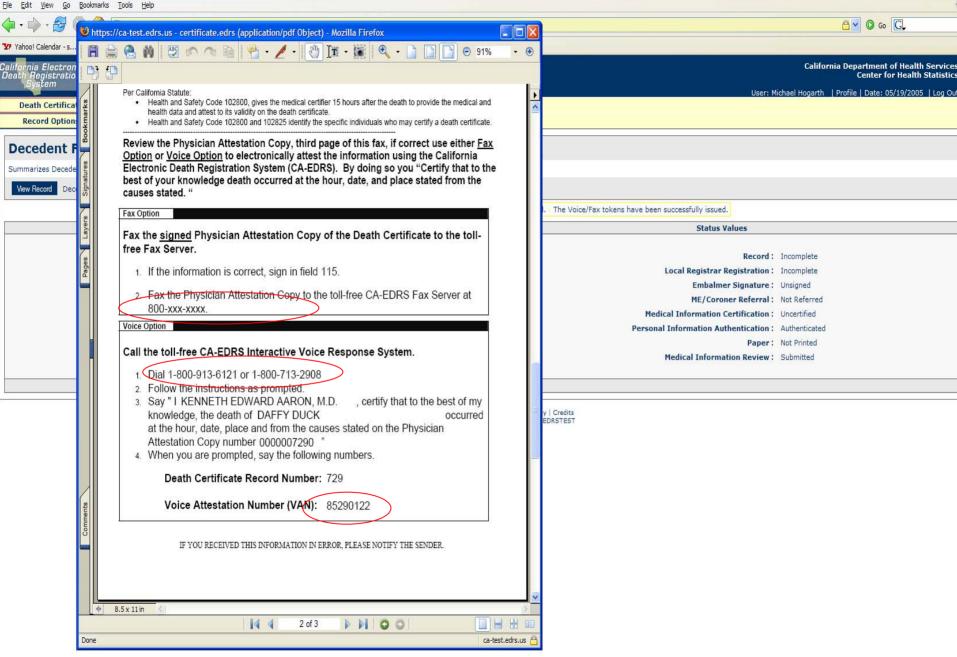
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CA-EDRS 2005

- CA-EDRS Project
 - On time, on budget delivered Dec 28 2004 at a cost of \$1.98 million
 - >2,000 pages of project documentation, ~100,000 'lines of source code' in 10 months by a team of 7
- Today
 - ~ 800 active users
 - Implemented in 5 counties Yolo, Riverside, Sacramento, Imperial, Santa Clara
 - >150,000 2005 Death Certificates in the system >2,000 being added daily
 - Currently the largest and most active electronic death registration system in the US
 - > 250 'remotely attested' death certificates since Nov 1 2005
- Next
 - Continue Statewide rollout Monterey (Feb), Ventura (April), San Diego (May)...
 - Goal is counties accounting for 80% of certificates by Jul 2006
 - CalVDRS implement violent death reporting in EDRS
 - Refine and expand remote attestation
 - Causes of death issues (Cause Of Death Reviewer-- CODR)

Key Lessons

- Have a mechanism that allows everyone to "see" the scope creep and manage/control it
 - Scope Definition Document (SDD)
- If you have a death march project, negotiate acceptable compromises
 - -- staged delivery of functionality given the fixed deadline
 - -- if functionality is added, negotiate removal of other functionality or delivery in a later version
- Pick the right people
 - prioritize 'matching of personalities' over experience
 - complement skill sets (database, design, UI)
- Use highly iterative development methods -- Evolutionary (Agile) development
 - Pair programming
 - Deploy early and frequently
 - Automated regression testing
- Maintain close oversight and frequent benchmarking against project plan, resources, feature completion against the timeline

Credits

- Nathan Affleck
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THE END