HIS working group meeting

Wed 23 – Fri 25 Nov 2016

Geneva

Day 1

Opening by Panu Saaristo

Participants:

1 Rachel Meagher, Canadian Red Cross

2. Marta Trayner, Spanish Red Cross

3. Masaharu Nakade, Japan Red Cross

4 Panu Saristoo, IFRC, Teamleader

5 Olav Aasland, Norwegian Red Cross

6 Tonje Tingberg, Norwegian Red Cross

7 Anine Kongelf, Norwegian Red Cross

8 Karl Blanchet, LSTHM, Consultant

9 Sylvain Lyoen, ICRC, Business Project Manager Health Unit?????

10 Odile Vesco, ICRC, Head of ICRC Assistance Portfolio

11 Caroline Peruchot, ICRC, Hospital Management Specialist

12 Amanda McClelland, IFRC

**Session 1: HIS Architecture, Karl Blanchet**

Objectives of the 3-day workshop

* Learn about internal and external initiatives
* Make decisions on the HIS requirements and functions
* Make decisions on the next steps

Need to establish working groups with experts in the specific fields:

* data content
* legislation and data protection
* IT

Need the data to support decision making on a daily basis (clinicians) and strategically (HQ) – need a feedback loop

The vision for the new system was agreed in the workshop held in Tampere in June 2016

Today – defining the requirements of the HIS

**Session 2: Lessons learnt from the mini assessment of ODK HIS system in Greece, Paco Pozo**

Assessment conducted by LSHTM and Tonje Tingberg in October 2016, field visit to Greece clinics. Findings are in the presentation. A mini-evaluation of the ODK HIS was done using the deLone McLean HIS evaluation framework.

System: ODK data collection on tablet/smartphone following patient (triage, assessment, diagnosis, treatment); Pentaho used for data aggregation and dashboard development. Some patient groups (pregnant women, chronic patients) equipped with bar code card for continuum of care.

* Need a system which leaves no room for interpretation
* Carefully consider why a data field is needed (for what purpose is the data recorded?), e.g. presenting complaints vs. diagnosis information
* Patient record for follow up of individual care, or a database only for aggregated reporting/statistics?
* Need for data protection training in ERU delegates and staff
* Need clear understanding of system purpose
* Feedback loop must be included

Lessons learnt:

* Electronic system is feasible
* Should evolve from reporting system to HIS
* Need for unique RC HIS
* Clear purpose is required for the HIS
* Adapted to context
* Content to be agreed by professionals
* Use of standards (e.g. ICD-10)
* Unique ID technology (bar code, QR code, palm vein, iris?)
* EMR needed
* Data security and confidentiality needs to be in place (legal support required for this)

Karl Blanchet: The HIS functions – to be decided by working group:

* Reporting
* Electronic Medical Record, support clinicians in decision making and quality of care
* Facility based surveillance
* Facility management

**Session 3: Total Medical and Biological Information System (TOMBI) presentation by Japanese Red Cross**

Data collection and management tool for patients -includes an electronic medical record (EMR) but also allows for facility information management, e.g. drug stocks.

* Platform: ‘Filemaker’ – commercially available database software (licence req)
* Works on iOS and Windows
* Security challenges with ipads – saving password credentials on tablets/smartphones opens for data security breech (as tablet is used by multiple users)
* Algorithms for patient prioritisation
* Based on ICD-10 with search function, but also includes IFRC and MoH categories
* Links Reception, EMR and Pharmacy with statistics and reporting
* Not yet field tested, but ready for use for next ERU deployment
* Hosted on a local server (computer), can be synchronised with cloud server for back end support and back up
* Questions about encryption and data security
* A potential tool to be used in the interim of RCRCHIS development?

**Session 4: Canadian Red Cross HIS developments**

Provides in-depth patient data collection requirements for EMR

* ERU focus, facility based data collection
* Focused on content development of HIS
* Identifying IM needs- why collect data (IM needs), what data to collect (indicators) based on EMT standards. Global health indicators, , where/when will data be collected (workflow mapping)
	+ Operational planning in real time
	+ M&E
	+ Reporting
	+ Contributing to the evidence base for ERUs/EMTs in disasters/emergencies (epi of disasters)
	+ Planning/preparedness for future deployment
* Infectious disease categories are challenging and context dependent – must be adjustable to context (e.g. 9 in Nepal, 42 in Haiti)
* NCDs important to capture, as well as injury patterns for planning purposes (shipments)
* Also need to capture surgical interventions (in-patients)
* Capture referral info from facility patient was received from, and
* Capture discharge and post follow up – linking to other services/sectors and follow up, from in-patient to out-patient or community care/ or other services
* Set up for best practice/quality control practices, e.g. dispensing of PEP kit by consultant, not pharmacist
* Paper forms at point of care, then electronic data entry from the paper forms
* Forms for antenatal care, birth registrations, referral, x-ray etc
* Need for protocol for when personal data should be deleted, what data needs to be kept for how long, for accountability as well as other purposes

**Session 5: Minimum data set for EMTs – Skype presentation by Panu**

Update from Panu on the MDS working group, incl. web survey results.

Emphasising that the MDS is a minimum requirement, thus RC data collection must meet those criteria, but no limit for adding e.g. age categories. IFRC obligated to follow standards.

Panu will add documents to the google drive.

Discussions will continue in HK next week, where decisions will be made.

**Session 6: Objectives and functions of the RCHIS**

**Focusing on the Core functions of the HIS:**

* **Reporting**
	+ Daily clinical reporting
	+ Weekly management report
	+ HQ operational reporting
	+ Descriptive analysis
* **EMR**
	+ Outpatients
	+ MCH
	+ Surgery
	+ In-patients
	+ Lab
	+ X-ray
* **Facility based surveillance**
* **Facility management**
	+ Pharmaceuticals
	+ HR
	+ Equipment/consumables
* **Quality assurance / Accountability to patients**
	+ Patient records
	+ Risk management / critical incidents
* **Clinical prioritisation**

Need for the HIS system to support accountability and retrospective review of e.g. critical incidents

**Core objectives: - still a bit unclear. Left for now.**

* Appropriate services?
* Better services ?

**Review of forms**

1. **Outpatient consultation form**

Colour coded for admin/clinical fields

Must be able to save incomplete form

| **Logic** | **Variable** | **value** | **Essential / Non-essential**  | **Comment** |
| --- | --- | --- | --- | --- |
| Admin |  |  |  |  |
|  | New patient  | Y/N  | Ess. | Pull function from server to load previous patient registration (demographics) if revisit.  |
|  | Patient name | Name | Ess |  |
|  | Address |  | Ess |  |
|  | Transferred | Y/N | Ess  |  |
|  | Sex  | M/F/other | Ess  |  |
|  | DOB | Date  | Ess | Age is provided –  |
| If age = <16 | Guardian’s name  | Name | Ess | Triggered if age <16 guardian’s name) or UM is flagged |
| If age = <16 | Unaccompanied minor | Y/N | Ess |  |
| If age = <5 | Vaccination  |  |  |  |
| If patient is unconscious; no name; OR unaccompanied minor  | Picture/biometric |  | Ess  | Ref. unconscious patients, ebola experience. Add info field to explain when photo should be taken |
| TRIAGE? |  |  |  |  |
| If Sex = F and age = >10 <59 | Pregnant | Y/N |  |  |
| If age = <5 | MUAC |  | Ess | If <5 – provides normal, severe, extreme? |
| If age = <5 | Oedema  |  | ess |  |
| If age = <5 | Height |  | Non-ess | If <5 |
| If age = <5 | Weight  |  | Ess | If <5 |
|  | BP  |  | Ess | Use algorithms to prioritise triage: 1,2,3 – clinicians decision to prioritise upwards |
|  | HR |  | Ess |
|  | RR |  | Ess |
|  | SP02 |  | Ess |
|  | Temp |  | Ess |
|  | Pain scale  |  | Ess |
| If age = <5 Vaccinations: | MMR | Y/N | Ess |  |
| If age = <5 Vaccinations: | BCG | Y/N | Ess |  |
| If age = <5 Vaccinations: | Polio | Y/N | Ess |  |
| If age = <5 Vaccinations: | DPT | Y/N | Ess |  |
| TRIAGE LEVEL | 1-2-3-4-5 OR 1-2-3  | DEPENDING ON WHETHER IT IS AN EMERGENCY SITUATION OR NOT |  |  |
| CLINICAL  |  |  |  |  |
|  | Reason for consultation/chief complaint |  | Ess | Info button – what content to incl. history of complaint |
|  | Last Tetanus | <5y / 5-10y / >10y | Ess |  |
|  | Tetanus given | Y/N | Ess |  |
|  | Known HIV status | Pos/neg/unknown | Ess |  |
|  | Known TB status | Pos/neg/unknown | Ess |  |
|  | Previous surgeries |  | Ess |  |
|  | Known allergies |  | Ess | Specific for drug allergies. +button for more  |
|  | Any current chronic illness? |  | Ess |  |
| If new patient = Y | Current medications |  | Ess | Incl asking when they last had access to meds? |
| Physical  |  |  | Ess |  |
|  |  |  |  |  |
|  | Diagnosis | Use ICD-10 categories (simplified)  | Ess |  |
|  | General  | Normal/Abnormal: Comment | Ess |  |
|  | HEENT | Normal/Abnormal: Comment | Ess |  |
|  | Resp | Normal/Abnormal: Comment | Ess |  |
|  | CV | Normal/Abnormal: Comment | Ess |  |
|  | GI/GU | Normal/Abnormal: Comment | Ess |  |
|  | MSK | Normal/Abnormal: Comment | Ess |  |
|  | INTEG | Normal/Abnormal: Comment | Ess |  |
|  | NEURO | Normal/Abnormal: Comment | Ess |  |
|  | PSYCH | Normal/Abnormal: Comment | Ess |  |
|  | Injuries  | Directly related to disaster / Result of interpersonal violence/ Result of self-directed violence / Other  | Ess |  |
|  | **Use picture of body, draw on using codes for:**  | Injuries (allow selection of any of the below)Laceration – xPain – hash Deformity – circle Burn – AmputationContussion/Fracture |  |  |
| Diagnostics | HgB |  |  |  |
|  | Urine Chem-10 |  |  |  |
|  | Glucose |  |  |  |
|  | Urine BhCG |  |  |  |
|  | Malaria RDT  | +/- |  | If positive flagged at top |
|  | Pregnancy test | +/- |  | If positive flagged at top |
|  | Other |  |  |  |
|  |  |  |  |  |

Add consultant name? Or automatic from log in?

Day 2

Focus on DHIS2 with invited guests Lars Helge Overland (U of Oslo), Maria Vila (MSF Spain), and Rodolfo Melia

**Session 1: DHIS 2 Introduction (Lars)**

 [powerpoint]

* system allows for collecting, capturing managing and analyzing data (covers all stages of HIS)
* developed for health systems but generic to be used for other sectors
* open access, but not free to roll out; extensible through WEB APIs

100K monthly users

60+ countries

60+ NGOs

10 global/regional organizations

High adoption in Africa and Southeast Asia

typical usage is for HMIS, but also used for facility surveys, disease surveillance, IDSR, WASH, health programs, tracking of individuals (TB patients), licensing of medical doctors

range of non-health domains: education, forestry, etc.

not just focused on software - focus on capacity building - global training program (regional approach, building network)

System itself:

types of information - aggregate data, events, tracking

Data capture: sms, ussd, android, desktop

open/interoperable platform: expert tools, transactional systems (EMR, HR, mobile collection); analytics, data capture

extensibility through Apps - organizations can install their own apps into the system; allows for customization

allows for the creation of dashboards, pivot tables etc from selected indicators

[demonstration]

dashboard - charts, maps; different tabs with several dashboards

data collection/entry: file structure can be tailored to needs (geographical, organizational structure, etc)

can work offline; customizable by non-technical people

unit - data set selection - time period - set up a form

can create own indicators using various data elements

data visualizer - an easily scale up and down - from local level to regional, to global on certain data sets

Tonje: with a standardized system, could potentially pull information on different ERUs from several deployments in a time period (12 months)

Lars: dashboards can integrate aggregate, event and tracking information all in one

geographic/thematic mapping capacity - can add layers

e.g. for use event mapping - cases of cholera by location

Sylvain: can mapping from Tableau be integrated into platform? DHIS2 is working on this for next year

Tonje: what about Power BI? possible to input data into DHIS2 platform and export to Microsoft tools

Karl: you now have mobile data collection? yes -aggregate, event; tracking still in development

Event capture:e.g. facility-based mortality

went through data entry with parameters to describe an event

feedback loop possible with predetermined thresholds so that if a specific event should trigger a response, message/alert could be sent

tracker capture: can register individuals, build forms to needs e.g. medical record, and track other entities: supplies, equipment, staffing (start date, end date), etc…

Tonje: what about access - who has access to the data? has to be worked through on case-by-case basis

Paco: what about support? U of Oslo only deals with software itself - bugs, new developments, but support available through specialists, consultants - paid service for development purposes and ongoing support

**Session 2: PSI’s experience with DHIS2 (Rodolfo)**

PSI is the largest consumer of the DHIS2 - providing new development, supporting innovation

not doing emergency relief; use a commercial approach to provide health service - converting need into demand + building local capacity; support based on supplying franchisees, outlets

65+ countries - each have their own custom solution for monitoring and evaluation; needed help with data management

Client and data management - education and referrals by community workers; health services providers; client satisfaction; sales

Franchise management - providers, training

Quality control - medical services

PSI’s DHIS2 ecosystem:

standard web & android apps; combined with other core apps

23 countries are currently live; 6 in development

top-down: global stats are quite lightweight in terms of reporting requirements - high-level indicators; methodologies for client-based management are provided and other processes along with the technology (created a series of apps that are generic that can be tailored)

bottom-up: at country-level can expand on minimum guidelines provided by PSI; results against targets; managed by local DHIS2 administrators

Key process: service referral and provision at the franchise (largely paper-based)

1. IPC collects basic data + refers client (household visits)
2. client receives service

but with transition away from paper-based, data can be collected using USSD, android based tool (eReferral) - advantage of actually starting a file at community level; if client does not go to clinic, could potentially send sms reminder

example of enhanced data collection given: smart-phone interface quite sophisticated visual representations of malaria RDT results, and subsequent actions

Outputs: DHIS visualizations - starting point for decision-making; have a “data-to-action”

framework

Challenges after adopting DHIS2:

* demand greater than supply
	+ low availability of qualified DHIS specialist
	+ trained local staff is difficult to retain
* fast pace of change from UiO
* requests for sophisticated analysis
* supporting expanding user base
* controlling the overall cost

Karl: How many developers used in this whole process? 4-6 core people; but larger group that was looking at D2A framework (M&E people)

Tonje: each ERU could have a super-user

**Session 3: MSF experience with DHIS2 (Marta)**

MSF Spain is using DHIS2 for managing information from their projects.

Offline “deployment”

Currently 4 parallel MSF projects; customization and sometimes different technological solutions, but have common mechanism for common trouble-shooting, finding solutions together

HMIS: the operational hierarchy

HQ

Coordination (country-level, capital)

Project (coordination office in the field)

Health facilities

Health services

Health services configured in system: list of approx 25-30 (tracking data information)

[demonstration of MSF interface]

Flexible approach to data collection: have ‘core’ data set defined as Level 1 , but also have more data sets Level 2, Level 3 for contexts in which more information is available

Dashboards are very flexible - facilitating program management HQ to country-level (monthly level), and then to project level (weekly reporting), including selecting visual thresholds

Karl: when did this process start? content configuration took one year; content took the longest to decide on content, then the actual technical development; roll-out took around 10 months; went country by country(approx. 1 month per mission), project by project (3-4 days per project), changing the system - laptop with new software - clean shift with training of staff

but evolution ongoing

how to train users: high-turnover, usually no IT people; HMIS support by mail, skype, zendesk (4 people @ HQ); F2F training- HQ; remote training - field; briefings; standard MSF OCBA training; online course (most successful strategy to date - modular, activity-based, self-learning, self-paced, recognition and prizes, MSF OCBA Certificate, multilanguage) - approx. 6 months

PSI training methods? depends on whether training super users (new set-ups); final users, data-entry

Web Apps developed by MSF: adding functionality that was not there

* HMIS Dictionary – used to define indicators in data collection
* Project Configuration [demo]- this app is used every time a new project is started in order to adapt the language from that of DHIS2 (which is quite specific) to that of the organisation
* HMIS tally sheets – use to print data entry forms
* HMIS Management

**Online/offline architecture**:

Initially, it was not designed to work offline

At project level can work offline – if there is a local wifi network - data entry happens at this level

facilities still largely relies on paper-based, but capacity to use tablets exists (decision on use depends on context)

Next steps 2017 - MSF Amsterdam looking at metadata/synchronization capability; automatized data flow;

HMIS Dictionary [demo] - a type of SOP for use of the system; draws from configuration/structure but content can vary between MSFs

**Session 4: Overview of HIS Dashboards (Paco) - Powerpoint**

1. what type of data output is most relevant at each level of the organization?

Facility-level staff/local coordinator

* end of each day (+time trend): most urgent
	+ # deaths by diagnosis
	+ # critical incidents
	+ # discharges requiring f/u
* stratify by gender/age group/other?
* use reference and deviation points to compare
* end of each week: short term
	+ # patient visits by diagnosis
	+ # chronic patients
	+ drug stock level
* end of each month: longer term
	+ measures of performance
	+ measures of quality
	+ quality of data?
* comparison across clinics

Country-level coordinator

* daily, weekly, monthly; all info across clinics + time trend; use reference and deviation points to compare

HQ-level coordinator

* aggregated by operation

Based on the above, an initial assessment (to be refined) was made by the group of:

1. Reporting hierarchy:



2. The kind of data that should be reported on regularly at the facility -level, i.e. ERU level (see table below). It was noted that data collected should perhaps vary by function of operation (sudden onset of disasters, epidemics/outbreaks, complex humanitarian emergency, core health programming).

|  |  |
| --- | --- |
|  | DATA TO BE COLLECTED AT FACILITY LEVEL (ERU) |
| AT THE END OF EACH DAY | * NUMBER OF DEATHS BY CLINICAL DEPARTMENT
* NUMBER OF CONSULTATIONS BY DIAGNOSIS/SURGERIES/BIRTHS/XRAYS
* BED OCCUPANCY RATE (INDICATOR)
* NUMBER OF CRITICAL INCIDENTS (TBD)
* NUMBER OF NEW CASES BY TRIAGE LEVEL OF SEVERITY
* NUMBER OF NEW CASES BY DIAGNOSIS/FOCUS ON TOP TEN DIAGNOSIS
* NUMBER OF CONSULTATIONS PER STAFF TYPE (WORKLOAD INDICATOR)
* LIST OF INFECTIOUS (NOTIFIABLE) DISEASE ALERTS (WITH ID NUMBER)
* NUMBER OF DISCHARGES REQUIRING FOLLOW-UP

ALL DATA TO BE STRATIFIED BY GENDER/AGE GROUPUSE GRAPHS COMPARING DATA TO PREVIOUS DAYS (TIME TREND), CONSIDER THE USE OF REFERENCE POINTS (e.g. AVERAGE OF VALUES OVER LAST MONTH) TO BE ABLE TO COMPARE DAILY DATA TO THIS REFERENCE POINT. |
| AT THE END OF EACH WEEK | * ALL THE DATA REQUIRED DAILY BUT PRESENTED CUMULATIVELY OVER A WEEK
* WEEKLY NUMBER AND TYPE OF REFERRALS (IN/OUT)
* WEEKLY NUMBER OF CHRONIC/SURGERY PATIENTS/PREGNANT WOMEN DUE FOR FOLLOW-UP IN THE WEEK
* WEEKLY OPD INTERVENTIONS (TREATMENTS/VACCINATIONS/PSS CONSULTATIONS/BREASTFEEDING SESSIONS….)
* WEEKLY COMMUNITY OUTREACH INDICATORS
* WEEKLY STAFF WORKLOAD BY TYPE OF STAFF
* WEEKLY ESSENTIAL DRUG STOCK PRE-CRITICAL LEVEL (ORDER) (CLINIC/CENTRAL)
* WEEKLY ESSENTIAL CONSUMABLE PRE-CRITICAL LEVEL (ORDER) (CLINIC/CENTRAL)
* MAP ANY NUMBER OF RELEVANT VARIABLES

PATIENT INFORMATION SHOULD BE AVAILABLE STRATIFIED BY GENDER/AGE GROUPUSE GRAPHS COMPARING DATA TO PREVIOUS DAYS (TIME TREND), CONSIDER THE USE OF REFERENCE POINTS (e.g. AVERAGE OF VALUES OVER LAST MONTH) TO BE ABLE TO COMPARE DAILY DATA TO THIS REFERENCE POINT |
| AT THE END OF EACH MONTH | * ALL THE DATA REQUIRED WEEKLY BUT PRESENTED CUMULATIVELY OVER A MONTH
* AVERAGE LENGTH OF STAY
* ADMISSIONS/REFERRALS/DEATHS/DISCHARGES/ DISCHARGES A.M.A.
* NUMBER OF INFECTIONS POST-SURGERY
* NUMBER OF STOCK RUPTURES
* STAFFING WORKLOAD INDICATOR BY STAFF MEMBER
* COMPLETED FOLLOW-UPS/PLANNED FOLLOW-UPS
* NUMBER OF CHILDREN DELIVERED UNDER-TERM/UNDER-WEIGHT

ALL PATIENT INFORMATION STRATIFIED BY GENDER/AGE GROUPUSE GRAPHS COMPARING DATA TO PREVIOUS DAYS (TIME TREND), CONSIDER THE USE OF REFERENCE POINTS (e.g. AVERAGE OF VALUES OVER LAST MONTH) TO BE ABLE TO COMPARE DAILY DATA TO THIS REFERENCE POINT |

In order to select what information to report to higher levels of the hierarchy, the data reported above should be adapted to the reporting requirements of the higher levels of the hierarchy

**Session 5: Implementation planning (Paco)**

Major components

mobile data collection tools

database management system

analytical tools

Is there any existing solution that can provide customised….?

Mobile data collections tools: what are we looking for?

* collect patient data
* facility-related data
* guarantee recognition of pt identity
* types of data that can be handled (names, numbers, dates, barcodes, pictures..)
* data encryption for security
* store, download and upload data remotely w low band (EMR, patient f/u…)

Some commercial digital data collection tools [refer to PPT]

Database mgt systems:

* save, organise, retrieve large amounts of data
* multiple concurrent users
* easy user interface
* high security; encryption
* different levels of access
* handle multiple types of data

Examples: [refer to PPT]

Analytical tools:

* customized and diverse analyses
* mix and match analysis
* analysis of patient, facility and surveillance data
* analysis of info aggregated across facilities and other structures
* analysis of aggregated data over time
* calculation and tracking of key indicators
* thresholds and alerts (epidemiological and clinical)
* maps allowing access to different types of information
* exporting…

Examples: [refer to PPT]

options:

1. proprietary solutions
2. open-sourced based solutions

What might the HIS look like?

* mostly open source based solutions, use case driven
* depending on desired functionality, mix of tools

many different softwares, but as open-source they are continually evolving, tool can progress as developers are improving the system

but need professionals to make these softwares “speak” to each other

and to handle upgrades, testing and updates at field level - MSF Spain has decided to only do an annual update because even if developer does more frequent upgrades, testing can be heavy, and communication process…..

**Session 6: HIS Implementation (Karl)**

New product does not equal acceptance

Delone and McLean Framework [refer to PPT]

Data has to be trusted (quality)

System quality - no bugs

Service quality -

Use - monitoring user experience/satisfaction

Individual impact

Organizational impact

Enablers are important

Spirit Framework [refer to PPT]

* policy framework needs to exist, stakeholder interests, resources

Adopters Framework [refer to PPT]

* innovation: innovators - early adopters…..
* five attributes to ensure adoption:
1. relative advantage
2. compatibility - workload,
3. complexity - easy to use and understand
4. trialability - access to try with possibility of not using
5. observability - benefit is obvious to others

Adoption-Decision Process Framework [refer to PPT]

1. Knowledge
2. Persuasion
3. Decision
4. Implementation
5. Confirmation

PSI experience of implementation

* when value of a new system is clear to the user, then becomes very easy to convince
* if value of system is less clear and you need to increase adoption, PSI has used financial incentives
* need to demonstrate understanding of field-level problems and offer solutions that they value

MSF Spain

* importance of empowerment in how data analytics tools are set up; project level encouraged to play around with dashboards;
* strong communications/availability/support between HQ and field
* flexibility in scheduling timing of in-services
* individuals with medical and IT background used for roll-out
* many options as training tools

Karl: how do you actively assess user satisfaction?

MSF Spain - difficult to get feedback, needs to be

PSI: field-level interaction is important

Discussion on how to maintain this within the RCM - with potential of HIS to go beyond ERU, has potential applicability at level of health posts, clinics, hospitals, mobile clinics, etc… and with discussion on CBS, expands mandate of data management - will likely be a consortium approach, blended model, reference centre support? PNS or Regional cells?

IFRC has some hesitation on involvement of IM team in GVA for reason that there needs to be some learning on treatment of health information etc.

Will need project team identified for development of HIS capacity

needs to be resourced, IFRC identified that existing initiatives: RAMP, HMIS, CBS can potentially be grouped together at the secretariat to share IT/IM resources for coordination, maintenance, development, and revision of tools.

Additional ideas shared:

* keeping the ‘fail safe’ of paper-based tools
* and training clinical staff on both

ERU clinical delegates - sub-group that deploys as Surge can introduce this type of data collection at level of NS in small, medium scale operations (DREF, EA) where health services are part of the Plan of Action

Day 3: Friday 25 Nov

**Session 1: Data protection and patient ID and confidentiality**

Massimo XXX Data protection, ICRC - **\*\*see slides**

1. what is data protection

comes from the fundamental right of privacy and data protection (UN decl HR 1948, ICCPR, ECHR, )

Not just a council of Europe instrument, number of countries outside also considering membership, membership enables dataflow,

cloud based solutions may be hosted in a number of different jurisdictions, thus requires free dataflow

UN general assembly resolution 1990 states that some international agency are not subject

to national legislation, but follow guidelines.

What is personal data

Only personal data is covered by the data protection law

“Personal data” is not limited to individuals name

Pseudonymisation - anonymisation

1. Why is data protection on the rise
* new technologies have been characterised by making it easier, cheaper to generate, process and analyse massive amounts of data
* more difficult to predict what you can make of data in the future, and the implications of using data
* potential for exploitation of data
* regulators realised that current legislation not sufficient
* New regulations effective from May 2018

cash transfer programming

* data flow from programme, mobile phone operator, financial institutions, what are the risks involved
* being aware of risks impacting programme decisions (

DP and humanitarian action

* Amsterdam 2015 Resolution on data protection and humanitarian action

Brussels Privacy hub

* working series on DP and humanitarian action in relations to new tech, launched 2015
* response to lack of clear guidelines
* workshops to provide guidance to the humanitarian sector on various topics (Instant messaging, drones, biometrics, big data etc)
* aiming to produce a guidebook by summer 2017
1. the ICRC rules on personal data protection and Health data
* no rules on data protection
* immunity from jurisdiction
* therefore develop applicable legal framework to collect/store/transfer/
* statutes of ICRC changed to establish body to oversee and enforce(?) rules
* General principles:
	+ fair and lawful processing
	+ legitimate basis
	+ purpose specification
		- only used for the particular purpose
	+ data minimisation
		- only collect and keep the data necessary to achieve purpose
		- is it possible to pre-identify all purposes the data might be needed for? (ref. hum emergencies)
	+ data quality
		- identification, design, procedure and policy
	+ data retention
		- deletion once purpose is achieved
		- archiving vs. long term storage (for auditing, legal reasons)
* Off the shelves solutions - big cloud solutions, may not declare where servers and processors are -

Health data

* always sensitive
* additional security measures imposed
* some data processes that can only happen on the basis on consent
* legal basis: vital interest of the individual
* for research: in general consent required, -
* Transparency/Information
	+ contact info to staff in charge
* Right of access
	+ who has access when and how
* security
	+ physical (protection of room, devices) and digital security (personal data kept separate from other types, access rights, authorisation/authentication, encryption, historical log of database required, portable or removable devices should be used to store documents containing health data, health data must be transferred to secure database as soon as reasonably practical

Best practice of EMR in conflict with DP principles? Needing 2-3 identifiers to ensure the right patient?

MSFs practice? Ethical committee manages these processes. Can we learn from MSF?

Karl: Possible to access ICRC’s health data protection? Brussels WG does not cover health data

Lesley (legal, IFRC) represented IFRC in the Brussels WG

Karl: Do we need a written procedure for RCHIS?

ICRC: Yes, a terms of use for the tool. Needs to be signed by staff in charge. Documents SOP for use of RCHIS, incl access issues

2 sides to the data debate: Data protection vs increased sharing

Amanda: initiatives on data sharing in emergencies - will balance DP for patient rights

Push within the RC to release everything on HDX (incl assessment data) for “the common good” and improved operations

Karl: Can ICRC share their terms of use that has just been written up for their programme. to translate sop to legal terminology.

Panu: enough to share the structure

Tonje will follow up with Massimo to see what is possible to share.

ICRC: Might need to hire a consultant to do impact and risk assessment and write up terms of use.

Suggested companies? IOM, UNHCR, ICRC, IFRC the orgs mainly working on this. ICRC have worked with consultants hired by UNHCR

Might take a couple of months to execute impact and risk assessment, once the tool is complete.

Sylvain: Always better to include data protection up front, rather than late in the process

Karl: Need to include data protection experts from early next year. In the design phase

**Session 2: Christoph Bron, Veintree, Ethical Biometrics**

“the first privacy-friendly biometric authentication method”

developed by EPFI, Idiap, HEs-so

it’s not about identification,

but geolocation, authentication

the coded mapping of palm vein network (or other body part) as “the future authentication solution”. using mobile phone camera and UV light, creates a unique code. will be recreated if you encounter the same person. add additional information (medical notes, responsible doctor etc)

reconciling biometrics and protection of privacy?

suggested used for

* disaster management (beneficiary registration and distribution data)
* primary care management by remote assistance

Karl: Not an ambition to have a unique database in general, need a unique database for the population we serve

Massimo: in terms of data protection, biometrics is identification.

Action point: Need to develop DP policy and procedures

**Session 3:**

Karl: In principle plan to utilise open source tools?

Amanda: that will require HR full time, min 2 staff members to manage RCHIS.

Sylvain: is there a business case developed?

Rachel: current model is NorCross supported for development.

Tonje: business case template requested from Panu. Amanda will follow up and provide this to Tonje.

Amanda: If moving management of the system IFRC once development is finalised, a business case is required. If managed by NorCross then follow NorCross procedures.

Tonje: HISWG will recommend system specification and management plan to the ERUWG, but decision is premature.

Rachel: Coordination function of IFRC speaks for IFRC managing it, but the case can also be made for a NS to host the service.

Amanda: HIS can be linked to CBS and RAMP developments, but there are obstacles.

Tonje: NorCross has committed to supporting the development process, but once cost estimation is done asking for shared costing for the technical developments.

Business plan must incl 3-5 development mapping,testing, adding features, support and maintenance

|  |  |  |  |
| --- | --- | --- | --- |
| **Action Point / Deliverable** | **Deadline** | **Output** | **Responsible** |
| Connect Japan with experienced developers to check compatibility * connecting to dhis2
* develop android code
 | December 2016 | cost analysis of utilising TOMBI | Karl and Dr Nakade |
| Revise concept paper for RCHIS for external sharing | Dec 2016 | CN  | Karl  |
| Write and share evaluation guidelines for HIS evaluation | Dec 2016 | Prep Haiti TOMBI evaluation | Paco  |
| Test and evaluate TOMBI in Haiti ERU | Dec 2016 / January 2017  |  | JRC and CanCross |
| Contact French, Finnish and German ERU Coordinator | December 2016 | Information on development | Tonje |
| Short term Action Plan (2017 plan) (including estimated costs);  | End January 2017 |  | Karl and Paco |
| Conference call to finalise 2017 plan | Beg. Jan 2017 | 2017 Plan  | Tonje |
| Identify contact persons in IFRC Dept of * Legal
* IM
* IT
* Med log
 | January 2017 | list of contact names | Amanda |
| Establish sub-WG in * Legal
 | Jan 2017 |  | Amanda |
| Establish sub-WG in * Data Content
 | Dec 2017 |  | Rachel |
| Establish sub-WG in * Technology
 | January 2017 |  | Tonje |
| Webex ERU TWG for update on development 2016 and plans for 2017 | Dec 2016 | Update TWG on project progress and invite them to Oslo | Tonje |
| Legal subgroup workshop | February 2017 |  | Amanda |
| Data content subgroup workshop (combined) | March 2017 |  | Norwegian RC |
| Technology subgroup workshop (combined) | March 2017 |  | Norwegian RC |
| Teleconference about 5 year plan | April 2017 |  | Tonje |
| Long term sustainability model (2020 and beyond vision): justification, stakeholder mapping, measures of performance, sustainability, support services (training,...), risk assessment, milestones, budget, scenarios, TOR for PM/team | May 2017 | 5-year action plan | Tonje |
| Present RCHIS 5 year plan at ERU TWG meeting  | June 2017 |  | Tonje |
| Functional requirement specifications Document (DP by design, use case approach) | May 2017 | Full document | HISWG (DP consultant) |
| Develop RCHIS Policy and terms of use procedures on data protection by design | May 2017 | Full document | HISWG  |
| Quality assurance document | June 2017 | Full doc | Tonje |
| Request for proposal  | June 2017 | System requirement specification, plan, budget, support | JRC/SpanishRC with IT department IFRC |
| Selection of developers | July 2017 |  | Tonje |
| RCHIS system prototype delivered | October 2017 |  | Tonje |
| Start piloting new system  | November 2017 |  |  |

Rachel: Who could be an IFRC IT reference person?

Amanda: Would not need a budget for consulting in the development, but needs to be involved in the system requirement for hosting etc.

Legal guidelines:

* tonje to follow up with Rodolfo (PSI) and Marta (MSF) to access their legal/ethics frameworks for HIS