Planning Digital Preservation for e-Health using Preservation Network Models

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Science and Technology Facilities Council

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Why Preserve Health Records?

1) patient;

Period: patient's lifetime;

Purpose: to improve medical care

2) hospital;

Period: defined by regulation,

Purpose: conform to regulations and avoid penalty fines

3) patient's family;

Period: successive generations;

Purpose: to identify genetically transmitted illnesses

4) public;

Period: indefinitely,

Purpose: data for epidemiology studies.

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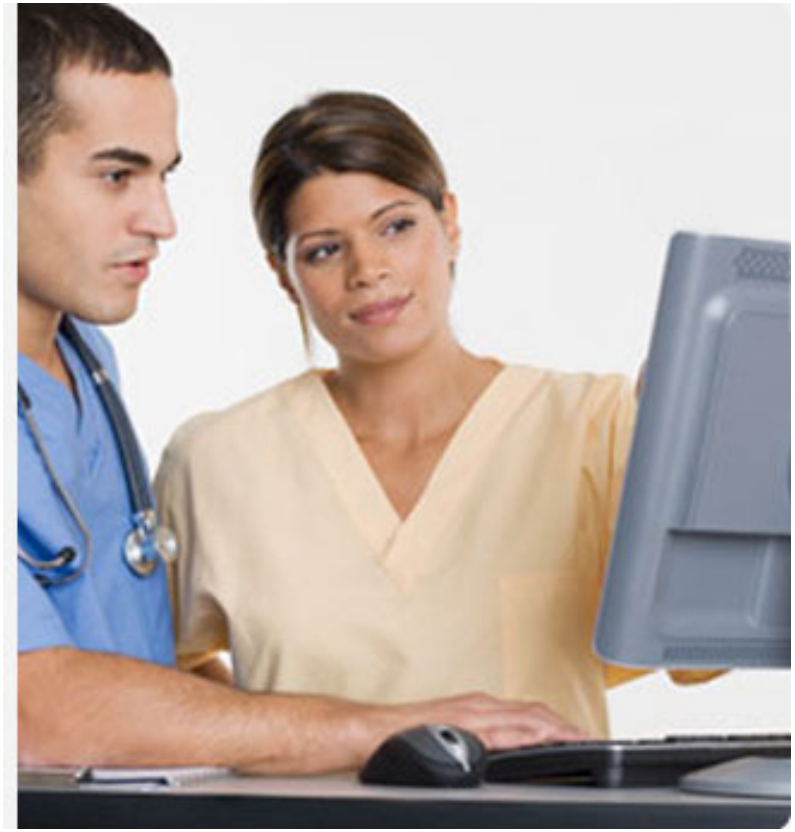
What Health Records ?

- Health Records
  - Moving from paper to computer
  - Remain PDF style paper forms



HEALTH RECORD

PLEASE ANSWER ALL QUESTIONS. Type or print answers. This information is confidential and will not be released without your written consent.
Return this form to: *University of the Incarnate Word, Health Services, 4301 Broadway, San Antonio, Texas 78209, Phone (210) 829-6017.*

OFFICE USE ONLY
Date Received _____
Health Record ❑
Immunizations ❑
Insurance Card ❑

CLASSIFICATION
Date Enrolled _____
First Year ❑
Sophomore ❑
Junior ❑
Senior ❑
Graduate ❑
Transfer ❑
International ❑

NAME: _____ (Last / First / Middle)
Social Security No. _____ Date Of Birth _____ Gender _____ Marital _____
Home Address _____
City _____ State _____ Zip _____
Phone No. _____ Citizenship _____ Are you a Military Dependent? _____
PARENT, GUARDIAN OR SPOUSE (please circle)
_____ (Last / First / Middle)
Home Address _____
City _____ State _____ Zip _____
Phone No. _____ (Daytime) (Evening)

FAMILY HISTORY
Father Living Deceased
Age at Death _____
Cause of Death _____
Occupation _____
Mother Living Deceased
Age at Death _____
Cause of Death _____
Occupation _____
Siblings Number Living ___ Number Deceased ___
Age at Death _____
Cause of Death _____

Have any of your relatives had any of the following?

	Circle Yes or No	Relationship (if yes)
No	Arthritis	Yes _____
No	Asthma	Yes _____
No	Heart Disease	Yes _____
No	Cancer	Yes _____
No	Diabetes	Yes _____
No	Kidney Disease	Yes _____
No	Seizure Disorder	Yes _____
No	Emotional Illness	Yes _____
No	Tuberculosis	Yes _____
No	Other: Specify	Yes _____

Personal Medical History: Have You Or Do You Have:

❑ Asthma
❑ Cancer
❑ Diabetes
❑ Chronic Cough
❑ Tuberculosis
❑ Heart Disease
❑ Kidney/Bladder Disease
❑ Bone Joint Disease
❑ Sexually Transmitted Disease
❑ Seizures/Blackouts
❑ Anxiety/Depression
❑ Head Injury
❑ Recurrent Headaches
❑ Hi/Low Blood Pressure
❑ Gum/Dental Disorder
❑ Peptic Ulcer
❑ Eating Disorder
❑ Chicken Pox
❑ Bleeding Disorder
❑ Hepatitis/Jaundice
❑ Recent Weight Change
❑ Infectious Mononucleosis
❑ Psychiatric Treatment
❑ Wear Contact Lenses
❑ Wear Hearing Aid
❑ Other Handicaps/Needs
❑ Tonsillectomy
❑ Appendectomy
❑ Hernia Repair
❑ Other Operations
❑ Female Menstrual Problems
❑ Scarlet Fever
❑ German Measles (Rubella)
❑ Measles (Rubella)
❑ Mumps
❑ Malaria

ALLERGIES
❑ Penicillin
❑ Sulfa
❑ Codeine
❑ Aspirin
❑ Foods
❑ Seasonal Pollen
❑ Wasp/Bee Stings
❑ Other:

Please Comment On Any Checked Boxes: (Include Explanation and Dates of Illness) _____

STATEMENT OF AUTHORIZATION

I authorize the Student Health Service at the University of the Incarnate Word to administer medical services, and to perform routine and emergency diagnostic and therapeutic procedures as deemed necessary by duly licensed medical personnel.

Student Signature _____ Date

Parent/Guardian Signature if student is under 18 _____ Date

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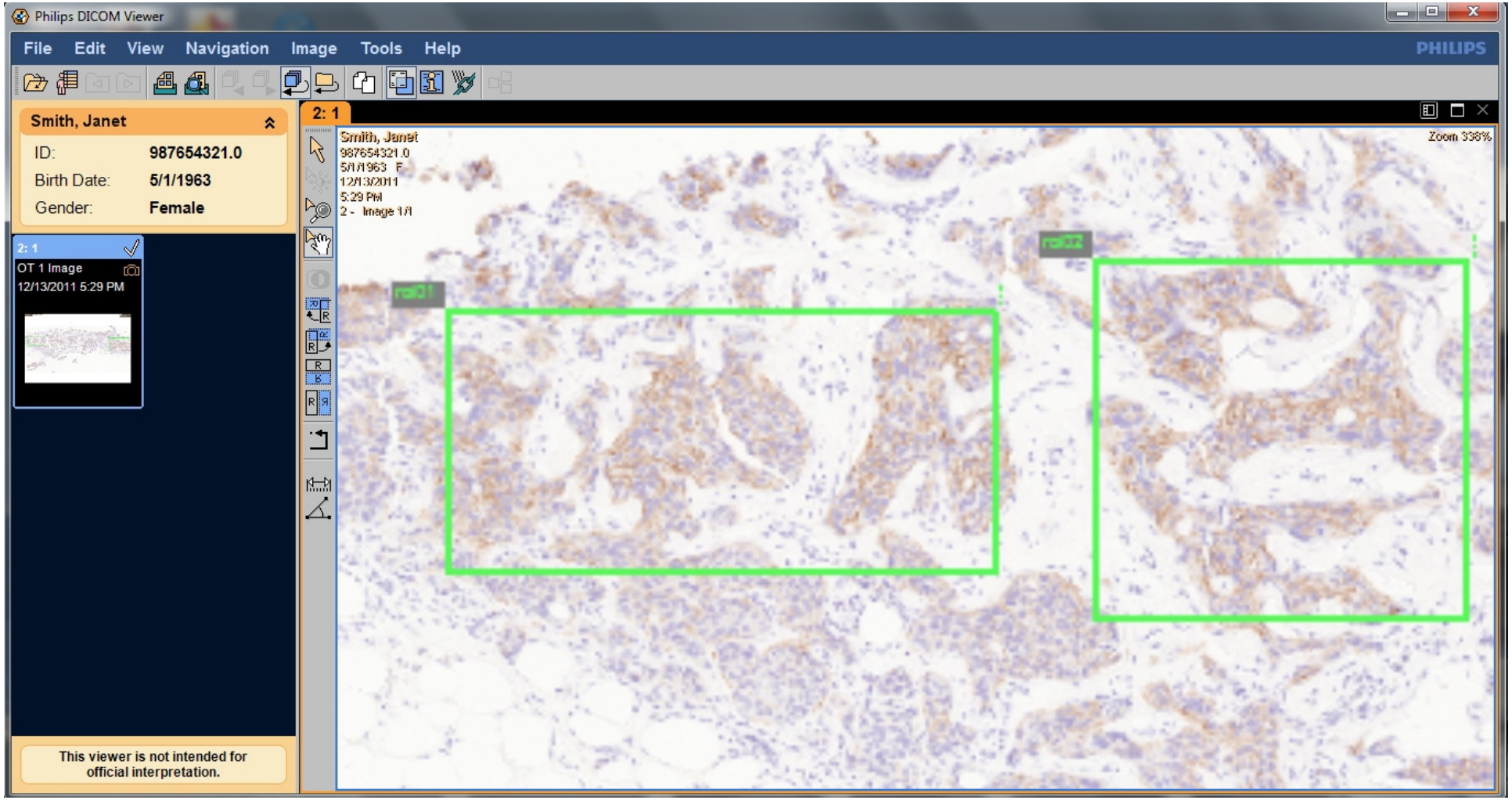
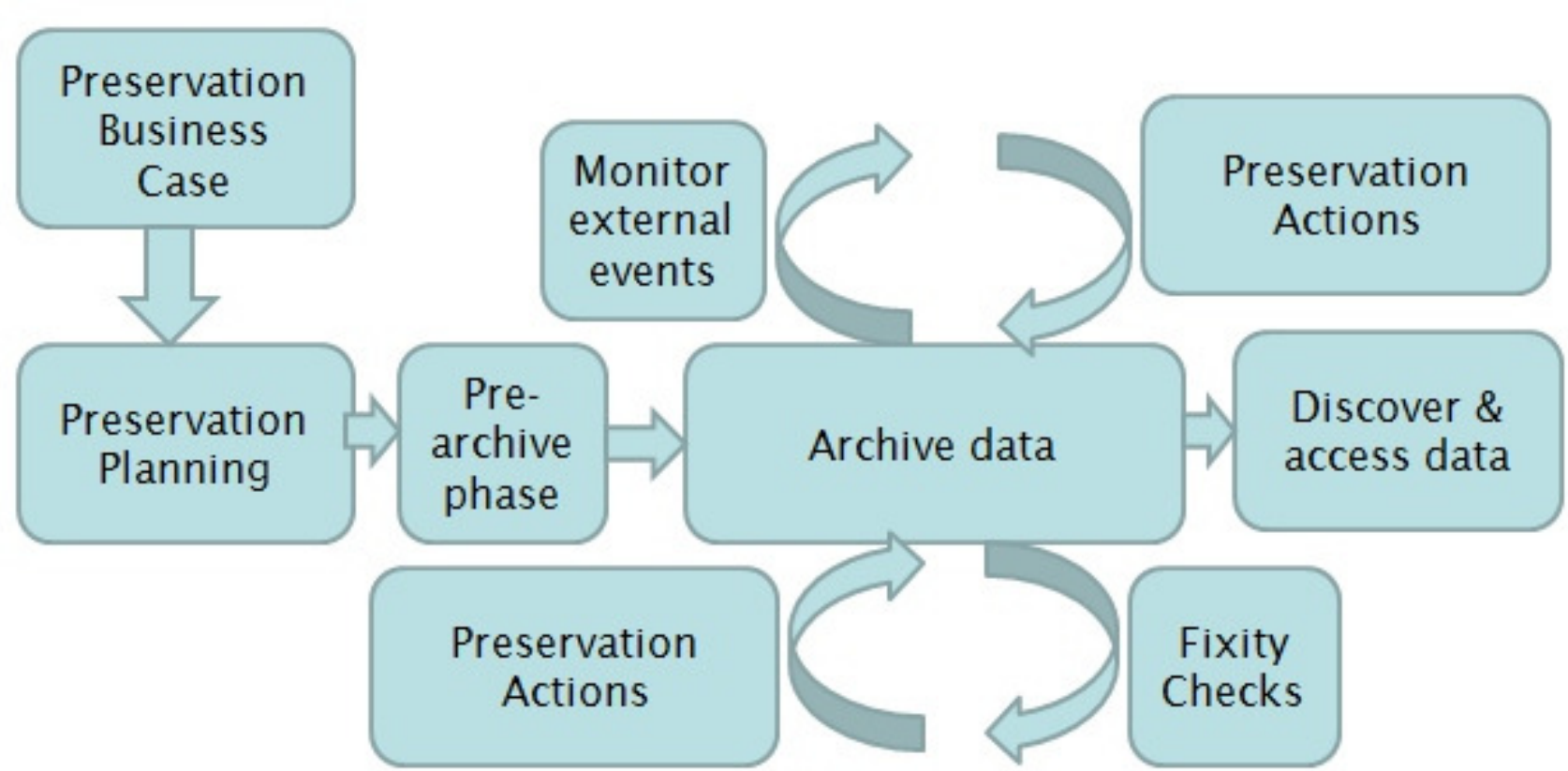
Health record – beyond the PDF

- Records associated with many files
- Pathology images in DICOM format – DICOM viewer ?



Preservation Process



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Which preservation strategy ?

- 1) preserve the data in its current format and assume that it will be usable when required (archive strategy);
- 2) preserve the data in its current format and a description of the format which can be used by a generic emulation tool to use it when required, and assume that the emulation tool will be available when required (emulation strategy);
- 3) migrate the data to one of a few supported formats which can be migrated again later if potential format obsolescence is identified in order to ensure that the data is always in a format which can be used (migration strategy);
- 4) store the data and the tools to use them, and the libraries, operating systems, etc. which those tools depend on, and virtualise the platform to run the tools on the data when required (virtualisation strategy).

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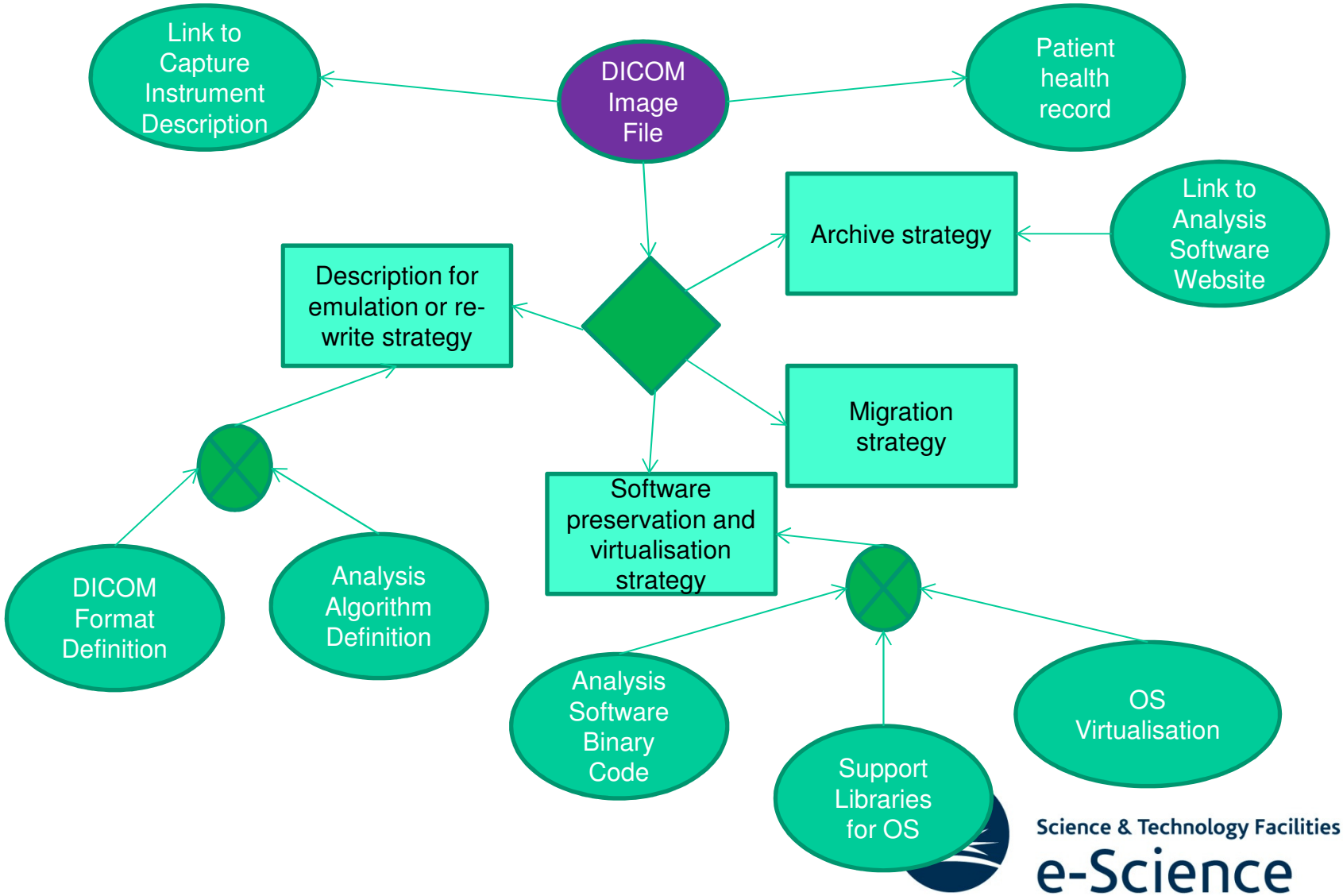
Preservation Network Model (PNM)



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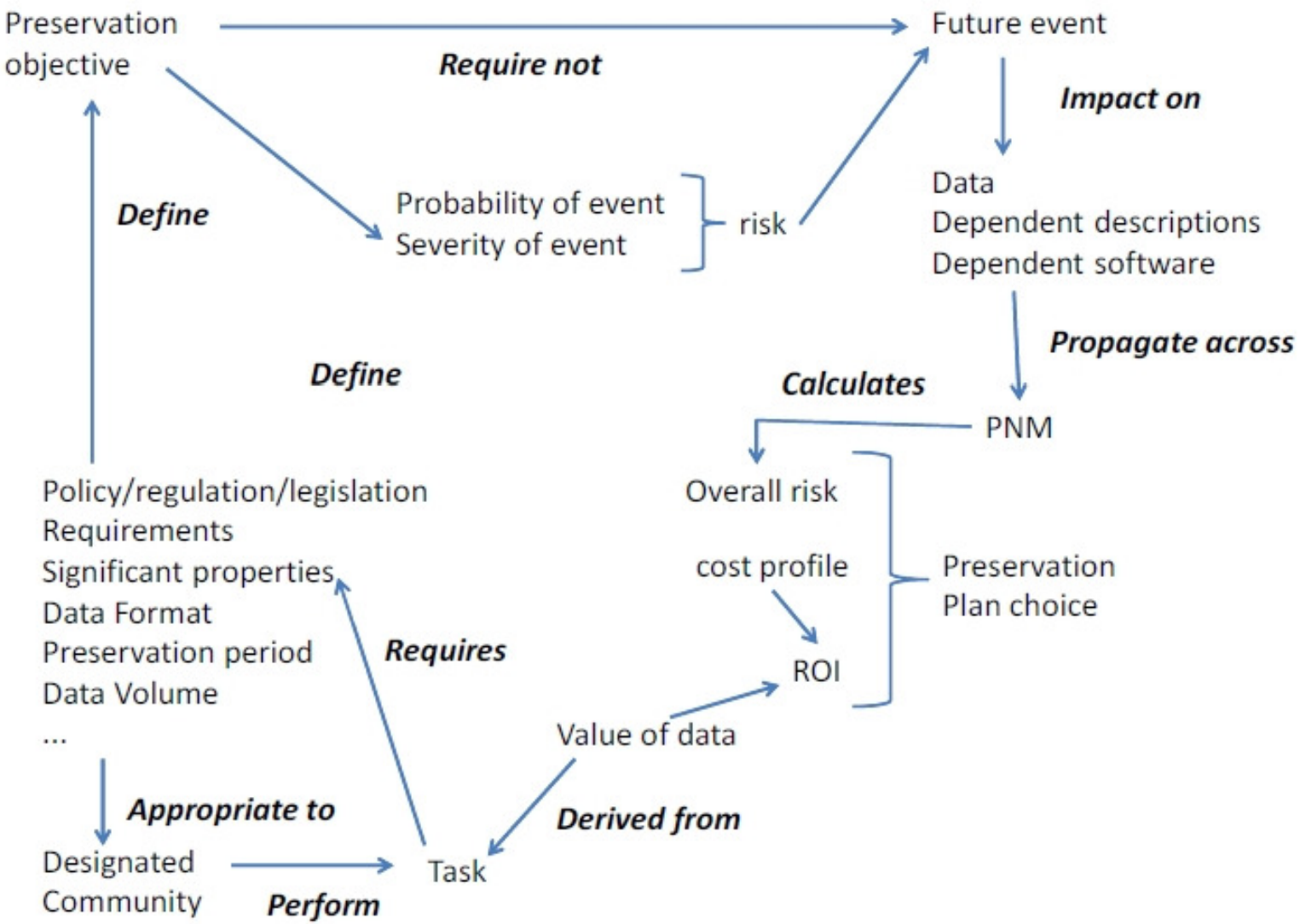
Risk Based Preservation Planning



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Conclusion and outlook

- Tools are under development to support this methodology:

1) PNM editor to generate RDF representations of the preservation network model;
2) planning tool to generate alternative preservation plans from the PNM;
3) cost modelling tool to estimate the cost of each plan;
4) ROI tool to subtract cost from value of data to give ROI;

- **Weakness – how to estimate potential future value of data - probability of occurrence of reasons and their value.**

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Questions ?

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