## 11th Dec 2017- Seminar room Byrne House, University of Exeter

3-5pm Chloe Silverman – Egenis seminar.

## What is an Ethical Autism Research Culture?

Chair, Sabina Leonelli

There is currently little formal guidance for autism researchers seeking to design studies in an ethically conscientious fashion, despite a history of research designs that have incorporated potentially harmful assumptions about the causes and consequences of autism. Published work on autism research ethics has focused primarily on research conduct and responsible communication of findings, with less focus on research design ethics. This persists despite lively conversations and substantive recommendations on this topic from self-advocates, as well as suggestive findings on how research design can be affected by a range of community engagement practices. This talk describes a project still in its early stages that aims to use stakeholder consultation to generate a set of guidelines for ethical autism research design. By comparing the perspectives and publications of researchers who do and do not use forms of community engagement, the project will evaluate whether and how such practices affect research design ethics. One goal of this project is to generate evidence of how community engagement (as one type of ethical research design practice) might benefit both stakeholders and researchers, yielding findings that may be both more innovative and more robust.

7pm Dinner at Comptoir Libanais

Overnight for non-locals at <u>Jury's Inn Exeter</u>

## **Exploring Diagnosis Advisory meeting Dec 12th**

## **Seminar room Byrne House**

9.15 am Ginny Russell Intro to Ex Dx

9.30 am Steven Kapp-book/ Jeremy Routledge-films

Discussion/feedback -all

10.45 Tea

11am Jennie Hayes–Diagnosis of autism as a social process–studies with clinicians (tbc)

Thomas Lister- Diagnosis of autism and self-identification—study with autistic adults

(title tbc)

Discussion/feedback - all

12.00pm Lunch

1pm Ginny Russell -Autistic Strengths? – A qualitative study. Chair- Joel Kruger

1.30pm Panel discussion–Virginia Bovell, Tom Pittwood, Adam Feinstein on theme of

strengths.

2 pm Discussion/feedback – all

2.30pm Labelling study - Rhianna White (can feedback over tea)

2.45pm Tea

3pm

Katherine Runswick Cole-The functions of impairment labels with a focus on autism

Sami Timini – What is autism and does it matter?

Discussant John Dupre TBC. Chair, Susan Kelly.

Finish by 4.30pm.